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“So far down the track”: The phenomenological exploration of a supportive model of care for patients being considered for colorectal liver resection

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Abstract

This study explores the experiences of patients being considered for colorectal liver resection combined with the views of health professionals involved in this pathway with the sole intention of developing a supportive model of care for future patients.

The treatment of colorectal liver metastases (CRLM) has continued to evolve with promising pace (Stintzig 2018, Adam & Kitano 2019). For many patients, multimodal treatment including surgery and systemic anti-cancer therapy have created a paradigm shift in how a diagnosis of secondary colorectal liver disease is viewed. With this in mind, there is a necessity to develop patient services to be responsive to the needs of those living longer with secondary cancer (Kmietowicz 2015), particularly as issues of survivorship begin to emerge (Haggstrom & Cheung 2019). More than 50% of patients with colorectal cancer will develop CRLM at some point in their disease trajectory (Chow & Chok 2019), making the prospect of radical treatments certainly attractive. Yet, only 20-30% people with CRLM will be eligible for surgery (Manfredi et al 2006, Valderrama-Treviño et al 2017) and as such, issues of uncertainty can punctuate the pathway to potential surgery and beyond. Observationally, working as a nurse specialist within the multidisciplinary colorectal cancer team, it is evident that the pathway to liver resection can be especially demanding for patients, as patients hold in tension the knowledge that their cancer has metastasised with the hope for containment or even cure. However, there is little evidence from the literature to support such observations or how the needs of these patients can best be met.

In order to address unanswered questions regarding support, this study is primarily a phenomenological inquiry, staged around the examination of an existing pathway in Phase 1 of the study. In response to this phase, an interim period allowed for the development of a new support structure, led by the specialist nursing team, incorporating a systematic telephone model, development of a patient literature series and development of a patient buddy service. Phase 2 of the study allowed for evaluation of this service development. Both phases include qualitative data from interviews with patients who had been considered for CRLM as well as focus group data from health professionals involved with the pathway.

The study is influenced by hermeneutic phenomenology as developed by the twentieth century philosopher, Hans-Georg Gadamer (1960, 1996), in order to guide both method and meaning throughout the progress of the work detailed in the thesis. It draws on the tenets of Gadamer's 'fusion of horizons' (1960) as a fitting vantage point incorporating different viewpoints and my own having insider-outsider knowledge as the researcher. It also latterly brings in the relevance of Frank's illness narrative (1995). Three overarching themes were identified from Phase 1 which were embedded in the pathway and specific aspects were used to develop the support model;

- a path of expectation; an enduring horizon
- the companion of uncertainty; a unified horizon
- a journey of personal understanding; an individual horizon

Moreover, complete analysis from both sets of data uncovered a central strand in these unique and differing patient experiences which translated these experiences into stories of hope. Hope was the mechanism used throughout the pathway and expectation, uncertainty and understanding were components of that hope. This calls into question how we, as health professionals, view hope in metastatic surgery of a radical nature and how we can foster it amidst uncertainty.

Lay summary

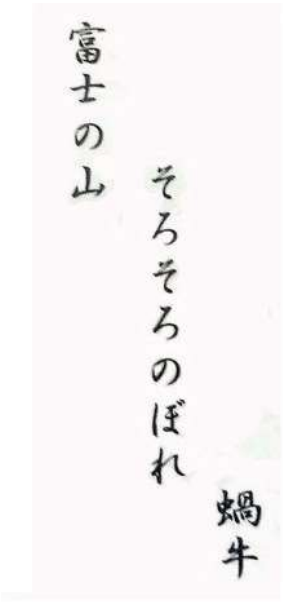
The management of bowel cancer continues to develop with increasing options for treating cancer that has spread (metastasised) to the liver. The use of liver resection (surgical removal of part of the liver) can be used to treat and in some cases cure bowel cancer that has metastasised to the liver. The liver is the most common site for bowel cancer to spread to and approximately 30% of people, with such spread, will be eligible for surgical resection. Yet, the process of workup to this surgery can be challenging for patients and their families as the route to surgery is full of uncertainty. This study uses a research approach, named hermeneutic phenomenology, to understand more about the experiences of patients who are being considered for colorectal liver resection. The research also explores the views and experiences of health professionals. The researcher's position with insider knowledge of the care also has a bearing on the study to help with interpretation of the findings. The overall goal of the research is to enhance and improve the services for, and experiences of, future patients.

The study was conducted in 2 phases. Phase 1 involved the interviewing of 16 patients who had been considered for the liver resection described above, 12 of whom proceeded to liver resection, and 4 who did not. A focus group was also conducted with health care professionals involved in the management of patients with potentially operable liver metastases. The findings from the interviews and focus group were reviewed during an interim period, allowing for a new support pathway to be established. This involved a telephone support service run by the specialist nursing team, the development of a leaflet series and the setting up of a patient 'buddy' service. Phase 2 of the study involved evaluating the new service by the interviewing of a further 16 patients and conducting a second health professional focus group. The overall analysis showed that these experiences could be seen as stories of hope involving expectation, uncertainty and understanding. Health professionals have a valuable role to play in facilitating patient hope amidst uncertainty and in providing a person centred and responsive service.

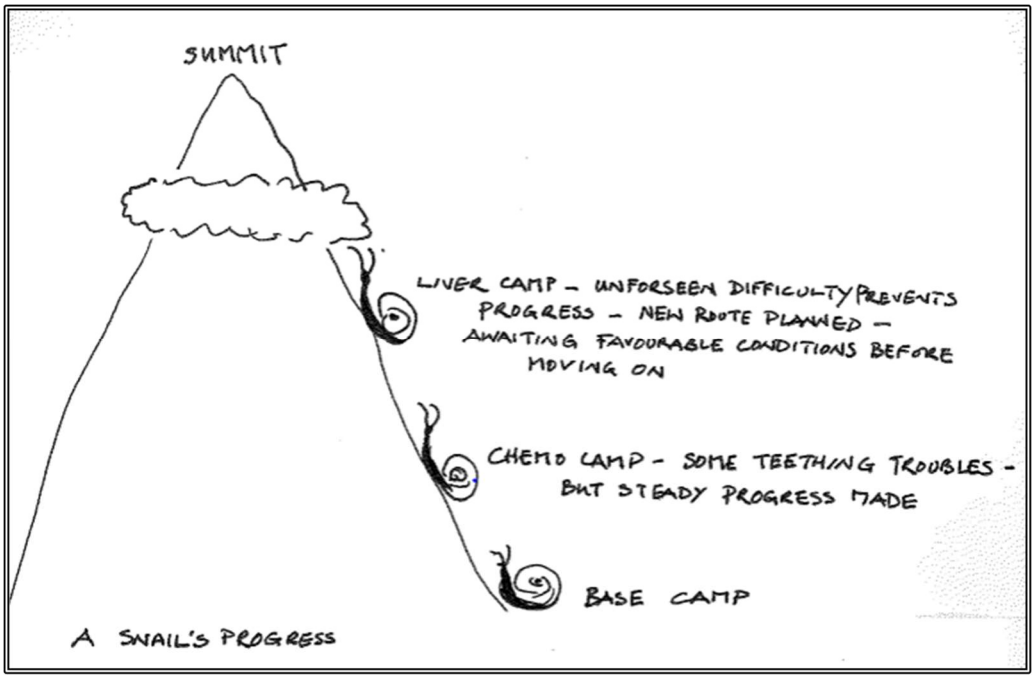
Through a patient's eyes…
the path to successful colorectal liver resection

O snail
Climb Mount Fuji,
but slowly, slowly

-- Kobayashi Issa



Issa (1763-1828)



With kind permission (2020) from previous patient on liver resection pathway (2014)
Reference to Issa's poem, (Issa, 2019).

Chapter 1

Introduction

"So far down the track now"

"We cannot understand without wanting to understand, that is, without wanting to let something be said...Understanding does not occur when we try to intercept what someone wants to say to us by claiming we already know it." (Gadamer 1964, p.101-102)

1.1 Chapter overview: Using unease

Most research is borne out of a sense of being ill at ease, a feeling that something is lacking or could be improved but so far the evidence remains insufficient to support that feeling. The catalyst for the work presented in this thesis is no different. It emanated from a feeling of being uneasy with the status quo around the support in the pathway for those being considered for surgical resection of colorectal liver metastases (CRLM). More than 50% of patients with colorectal cancer will develop CRLM, (García-Alfonso et al 2015). Surgery remains the only treatment to remove disease and improve survival (Choong & Ammori 2014, Chow & Chok 2019) although approximately only 20-30% people with CRLM will be eligible for surgery (Manfredi et al 2006, Valderrama-Treviño et al 2017). Developments in diagnostic radiology, surgery, and oncology have helped to maximise the number of patients being offered surgical liver resection (Venook & Curley 2019). These developments have also given way to a more encouraging picture of the treatment of CRLM and this has helped to deepen the overall understanding of what it means to live with colorectal liver metastases. This study is primarily a phenomenological inquiry, staged around the examination of an existing pathway and a revised pathway of support. The study is influenced by hermeneutic phenomenology as developed by the twentieth century philosopher, Hans-Georg Gadamer (1900-2002), in order to guide both method and meaning throughout the progress of the work detailed in the thesis.

While working within the colorectal multidisciplinary team, my and many of my colleagues' observations, regarding the CRLM pathway led to a feeling of dissatisfaction with the current support situation. Yet, my initial concern was that my vantage point of the CRLM pathway was more than that of purely observer. The position was one of observer yet with insider knowledge of how the pathway functioned and the resulting effect that both awareness of

metastatic disease and the process of that pathway could throw into the lives of those experiencing it first-hand. From this position as both observer and insider, it was evident that advances in medicine have created new possibilities for extending life while at the same time, creating new challenges in communicating what is right as well as what is possible. I could clearly identify with Atul Gawande and his sentiments expressed in *'Being Mortal'*, writing,

> *"People live longer and better than at any other time in history. But scientific advances have turned the process of aging and dying into medical experiences, matters to be managed by health care professionals. And we in the medical world have proved alarmingly unprepared for it." (Gawande, 2014a, p.6)*

An overall tension was apparent in situations borne out with patients holding onto the possibility of liver resection for CRLM and finally achieving that as a reality. These tensions were, from my perspective, exemplified at the outset in this pathway and throughout the process of being considered for liver resection. I wondered in all the virtue of advances, were we somehow implicitly asking patients to get on and live with a palpable sense of uncertainty, whilst being guilty of 'leaving them to it' and not fully realising how much through medical advances and our associated hospital systems we were asking of patients. Being immersed in the daily challenges of a varied practice, while ironically feeling like we were 'doing our job', could also blind us from any of real sense of what patients experienced.

What was not clear was, if these feelings of unease were also the experience of the patients on the receiving side of being considered for surgery, surgery that had the potential to either remove metastatic disease in their liver or potentially extend their life. For this reason, I wanted to utilise that feeling of unease I experienced as a nurse specialist working within the colorectal multidisciplinary team with as a catalyst for further inquiry. This was married up with a desire not just to inquire, but also to improve or enhance the existing pathway. What follows in this thesis is the experiential account of a total of thirty-two patients who were considered for CRLM, sixteen prior to introducing a revised support pathway and sixteen following revision of that pathway. It also includes accounts of multidisciplinary members of the colorectal cancer team who were involved with major treatment decisions in this pathway, captured in two focus groups. A grant with a pragmatic service improvement focus was secured to undertake this work. The primary aim of this study is to investigate how primarily patients and health care professionals experience the pathway to CRLM before

(Phase 1) and after a service improvement to that pathway (Phase 2). The service improvement is based upon the analysis of interviews and the focus group in Phase 1. A secondary aim is to assess whether additional support interventions can add benefit to the experience of being considered for CRLM surgery.

1.2 Merging perspectives

The last decade has given rise to the inclusion of patient viewpoints not only as a way of measuring performance quality and care outcomes but also as recognising the person as an individual at the centre of care (Raleigh et al 2015). Bate & Robert (2006) saw this inclusion of the patient viewpoint stemming from the turn of the millennium with a particular focus in service improvement incorporating the voice of the user. The white paper, *'Creating a patient-led NHS: Delivering the NHS Improvement Plan'*, (Department of Health, (DH), 2005) made direct reference to eliciting patient preferences and experiences and utilising patient involvement as a means to delivering the NHS Improvement Plan set out in 2004, (DH 2004). Yet, Bate & Robert (2006) recognised that much of this renewed focus on patient involvement had been around for a long time and *"unfortunately what it gains in longevity, it seems to lack in vitality and urgency"*" (p.307). What was often masking as experience was not really in-depth experience from the patient's account of using a service or of living with an illness but more of a fleeting capture of involvement in a world of survey culture and stakeholder events.

Moreover, this renewed inclusion and preoccupation with patient perspective, continued to gather momentum and evidenced itself further in a number of government reviews and policies recommending the need to review services by including measures of patient experience. These have included, the Darzi review (DH 2007), the NHS Outcomes Framework (DH 2014a) and the NHS Mandate (DH 2014b). Sadly, it has also included the report on the service failure at mid Staffordshire NHS Foundation Trust, commonly known as the Francis Inquiry (Mid Staffordshire NHS Foundation Trust Public Inquiry 2013). In this case, national and worldwide lessons have been learned in the way services are provided when there is a failure to put the patient and relevant others at the centre of care received. Extending out from patient and user perspective in health services is also a recognition that patient experience has a vital role to play in guiding research design (Boote et al 2013, Baxter et al 2016), such as that advocated through the role of the INVOLVE network, run by The National Institute of Health Research (NIHR) (NIHR 2017).

Bate & Robert (2006) strongly advocate experience-based design in health care which did more than focus on quality, effectiveness and safety. Having undertaken previous service development research, I had been attracted to this more holistic mindset, one in which as Bate & Robert promoted, the system was co-designed with the patient rather than redesigned around the patient. Bate & Robert distinguish between using experience rather than attitudes in research. The focus here ought to be on asking questions which elicit details of what the experience was like beyond the what was good and what was bad, which often only captures attitudes. Going beyond the surface of experience lends itself well to the process of phenomenological inquiry, where deeper elements of hidden meaning could also be discovered and attributed to processes at work in the CRLM pathway and how this might affect the lives of individuals. It is that knowledge of the experience that holds a sense of richness. It is not necessarily bound to any prior expertise and as such represents an unique angle.

> *"Knowledge of the experience, held only by the patient, is unique and precious." (Bate & Robert 2006, p.307)*

While recognition of the uniqueness of patient experience is rightly justified and is able to lend itself to many uses, my concern in obtaining patient experience alone is that the voice and insight of the health professional often seems disregarded and undervalued. Where there is appeal in patient co-design of services, what is debatable in the terms expressed by Bate & Roberts, is the idea that patients can input their perspectives and experiences on level terms with health professionals. My understanding is that is less to do with the weight and equality of experience offered by both but more to do about validating both experiences. What health professionals may lack in richness of personal experience they may make up for in observation and involvement of patient experiences over time, combined with an understanding of particular nuances of existing processes operating within given systems.

For this reason, I was attracted to the concept as expressed in the Gadamerian metaphor named the 'Fusion of Horizons' conveyed in Hans-Georg Gadamer's magnum opus, 'Truth and Method' which was written in his native language of German in 1960. It is important to note that I have not read the original due to my unfamiliarity with German, but that unless otherwise specified, I have used the 2013 English translation, revised by Weinsheimer & Marshall (Gadamer 2013). Through the concept of fused horizons, different interpretations of the experienced phenomenon are brought together through language to produce a shared

understanding of the experience of a given phenomenon (McManus Holroyd 2007), in this sense the CRLM pathway. The fusion of horizons could be a historical past position with a current horizon of the present or through merging different perspectives where there is a fusion of the familiar with the less familiar, a bridging in a gap of knowledge. Using this concept had immense value to me in this work because as I saw it, there was a fusion of horizons, on a number of levels. The first was the fusion between participant and self as researcher in order to bring about meaning between the dialogue in interviews and the focus group. The opening quotation of this chapter, from an essay written by Gadamer in 'Aesthetics and Hermeneutics' in 1964, highlights that we cannot understand if we assume that we know already. Language is the means through which these experiences are communicated and interpretation of this dialogue takes place through examination of language in the real time of interviews and in the transcripted text which reflects a concept central in Gadamer's hermeneutic phenomenology (Kafle 2013). These experiences often span many months and in some cases years, consuming a significant part of that individual's life cycle. I could therefore appreciate that these experiences were stories told from the starting point and wrapped up with the time of diagnosis when patients viewed their sense of health to have changed.

The second was the fusion of the experiences of the patients and health professionals, taking place in the standard pathway and the enhanced pathway. The third was the fusion required to utilise the findings from the standard pathway and work alongside colleagues to deliver a service change. The fourth but perhaps not exhaustive plane of fusion, was that as an insider with prior knowledge of the CRLM pathway, I had to be aware of my pre-existing *a priori* experience gained from working within the team while at the same time realising that I could not entirely separate or *bracket* that knowledge out as if I was a blank slate, as favoured by advocates of Husserlian phenomenology (Dowling 2007). It was at this point that the insider-outsider role of researcher merged. These different levels of fusion, each operated their own hermeneutical circle or circle of interpretation in order to work through the process of giving meaning to the text and shape for service improvement. As the process of finding meaning is iterative in nature involving a cyclical nature of induction, this is also true of the changing picture of a more aggressive treatment approach in colorectal metastatic disease. It is worth acknowledging, that this study is set within a rapidly developing treatment picture for secondary disease, something of which represents a new kind of understanding of metastatic disease and a new way of viewing these stories in the context of survivorship.

1.3 Developing a new concept of metastatic disease

The title of this chapter 'So far down the track, now", is taken from an interview conducted with a female participant who was interviewed in the first phase of patient interviews and was considered for liver surgery. Sadly, her disease progressed and liver resection became no longer feasible yet her quotation speaks into the present. The word 'now' can be seen to be connected with Heidegger's Daesin sense of being and "actuality in time" for this individual from his major work, 'Being and Time' in 1927 (Heidegger 2010, p.408). Here time takes on a personification element for this individual. It echoes the sense of anticipation, restlessness and hopefulness with the process of being considered for liver surgery, hinting at the idea of hurdles to be overcome which might have led to the goal of surgery. Time is hugely relevant and it is also pertinent to the idea that significant advances have been made in cancer treatment as a whole, which have given reason to hope.

Cancer treatment as a whole has come a considerable way since Sidney Farber's studies on the effects of folic acid and the resultant developments made in treating childhood acute lymphoblastic leukaemia in the late 1940s, which led to Sidney Farber being heralded as the father of modern day chemotherapy (Miller 2006). The last six decades in particular have seen considerable change with a particular focus on multi-modality treatment and with the emergence of newer targeted therapies on the pharmaceutical market (Binefa et al 2014, García-Alfonso et al 2015, Aziz et al 2017). As such the developed world has seen a major paradigm shift in the way in which in which cancer is treated. Improvements in sanitation, introduction of vaccination of infectious diseases and the establishment of formalised health care have all helped to play a part. Whereas fifty years ago, the main cause of death was infection (McKie 2015), now heart disease and cancer are major killers (Vineis & Wild 2013) with 1 in 4 expected to die of cancer and 1 in 2 who will develop cancer in a lifetime (Cancer Research UK 2017). Yet in common cancers, such as breast, colorectal and prostate, huge advances have given way to greater survival benefit. This is now an emerging picture for the management of metastatic disease, particularly in breast cancer and now gaining ground in colorectal.

The management of metastatic colorectal cancer is rapidly evolving. Over the last decade advancements in tumour staging, surgical technique and systemic chemotherapy (Pozzo et al 2008, Abdalla 2011, Haddad et al 2011) have pushed the boundaries of what was previously deemed palliative, to that of potentially curable disease. With no treatment a

median survival of 6-9 months would be expected but combined hepatic resection and chemotherapy has pushed a 5-year survival reported between 37-58% (Van Cutsem et al 2010, Morris et al 2010). Notably the majority of ground has been gained in CRLM resection but advances have also been seen in colorectal lung metastases resection and in the use of sequential resection for colorectal liver and lung metastases combined (Rajakannu 2015). In addition the use of targeted therapies in combination with pelvic clearance surgery has also seen a more aggressive approach in the management of colorectal peritoneal disease (März & Piso 2015). Overall this has led to a more promising picture in the management of colorectal metastases and has set the management within the context of the survivorship agenda and living with the presence of metastatic disease. While this is exciting, it is clearly not the uplifting treatment picture that is evident to us in practice which may be complicated further by disease staging or existing co-morbidities.

As disease management becomes more complex, so too does communicating the treatment pathway. On the one hand, life expectancy is longer which is giving way to a much fitter population in their seventh decade but how long at what resultant physical and economic cost can aggressive management of metastatic disease realistically take place? This brings into focus questions over the difficulty of practising realistic medicine as advocated by the Chief Medical Officer, Dr Catherine Calderwood, as valuable as that intent might be (The Scottish Government, 2016). This is simply because medical advances do not apply or bring benefit to all which brings us back to the often hidden and stark sentiments expressed by Gawande (2014b) that life is both unique and mortal. Attributing meaning to such major times in life when mortality may be more keenly felt, such as the potential to undergo liver resection for colorectal metastases, becomes more pertinent to understand.

1.4 Finding method, finding meaning

As outlined in this chapter, the methodology adopted in this thesis is a hermeneutical phenomenological inquiry predominantly around the patient's experience of being considered for a CRLM resection with reference to the health professional's experience of that pathway. The study is conducted in two phases. Phase 1 involves evaluation of an existing or standard pathway by way of 16 patient interviews and one health professional focus group. An interim phase allows for revision of that pathway based upon the findings in Phase 1. Phase 2 allows for further evaluation of the revised or enhanced pathway. In this way, an evaluation of experience takes place following an intervention. Therefore two sets

of findings will be presented. Collectively the findings may also give further depth of meaning to the experience of being considered for CRLM resection. The form of this thesis reflects the linear pragmatic progression of the study and also reflects the form of the stories being revealed, each starting with a clear beginning (diagnosis), a middle section (period of reflection over events) and an ending (outcome of treatment decision).

Chapter one has set out the introduction to the study, providing a backdrop as to the rationale and catalyst for the study. Chapter two provides a treatment overview of CRLM in order to provide the medical context to the advances made in this area. Chapter three details the relevant patient literature in this area and parallel areas of literature. In chapter four, the concept of hope is explored as relevant to the CRLM pathway which is punctuated with uncertainty. Chapter five presents the chosen research design and methodology for this study. Particular attention is given to show the appropriate use of hermeneutic phenomenological inquiry, which is heavily influenced by the work of Gadamer in 1960. In chapter six, the findings of Phase 1 are presented. The framework for analysis of findings detailed in chapter six and chapter eight have been guided by Smith et al (2009) in their approach known as Interpretative Phenomenological Analysis (IPA). These guiding principles have been used intuitively in an iterative fashion, creating a hermeneutic circle of interpretation to arrive at meaning which has then prompted a review of the existing pathway. Chapter seven details the interim period of service revision based on the findings in chapter six. Chapter eight returns to present the findings of the enhanced CRLM pathway in Phase 2. Finally, chapter nine brings together the findings in the discussion to show that these patient experiences are indeed stories on a continuum of hope.

1.5 Chapter summary

This introductory chapter has set the scene for the work contained in this thesis by reflecting upon the impetus for the research study, the changing treatment context of colorectal liver metastases and arguably the need to conceptualise colorectal metastatic disease differently than has been commonly viewed when the option of colorectal liver resection is feasible. It has also referred to the research methodology of hermeneutic phenomenology and analysis method of Interpretative Phenomenological Analysis (IPA) as fitting to this research. The importance of merging patient perspectives with health professionals and that of the researcher has been set out as an important element in this work, in order to embed patient experiences in the reality of emerging clinical practice for this patient population.

Chapter 2

The Nature and Management of Resectable Colorectal Liver Metastases

"We look for medicine to be an orderly field of knowledge and procedure. But it is not. It is an imperfect science, an enterprise of constantly changing knowledge, uncertain information, fallible individuals, and at the same time lives on the line…The gap between what we know and what we aim for persists. And this gap complicates everything we do." (Gawande, 2007, p.7)

2.1 Chapter overview

The treatment picture for colorectal liver metastases (CRLM) has seen dramatic change over the last three decades (Rees et al 2014, Kassahun 2015, Adam & Kitano 2019) and continues to evolve with rapid pace. No longer does a diagnosis of liver metastases from a colorectal cancer primary, necessarily mean treatment with palliative intent. Indeed, with careful patient selection, five-year survival rates from liver resection reported between 40-60% are encouraging in patients with liver limited disease (Abbas et al 2011, Twenzg & Aloia 2013, Dhir & Sassoon 2016). As such, the notion of survivorship is beginning to emerge for this patient population (Rees et al 2014). Yet, as one might expect in such an evolving area of treatment, there remain unresolved issues and controversies in the optimal management of resectable liver metastases. This is partly reflected by a lack of randomised controlled trials in this field and consequently, finding a unity of consensus among practitioners can be difficult (Brudvik et al 2016). A key consideration to this is that approximately 60%-70% of patients develop recurrent disease either in the liver or elsewhere and approximately one-third of these patients will die within 2 years of surgery (Jones et al 2012). The heterogenous outcome is of course reflected in patient health and biological characteristics of the tumour so this in turn makes patient selection all the more important. This chapter will set the scene for the context of the study by setting out the current management of resectable CRLM and outlining the main controversies in this area. In so doing, it will act as a precursor to the review of analytical and theoretical literature pertinent to the study as discussed in Chapter 3 and Chapter 4. This chapter will reflect upon the changing context of treatment for this patient group before considering the biomedical context and current treatment of resectable CRLM. Techniques to improve CRLM resection will also be discussed along with developments in surgery and associated outcome implications. While many of the challenges

of CRLM treatment will be blended throughout the different sections, the chapter will conclude with a summary of the main controversies in this field which are important to hold in balance as the patients' experiences of the pathway unfold in the remainder of the thesis.

2.2 The changing context of colorectal liver metastases treatment

The idea of rendering metastatic disease operable is hugely exciting, both in terms of treatment advances but more importantly for those living with the consequences of such disease. Liver metastasectomy, the removal of metastatic disease by surgery, has been recognised since the beginning of the 1980s as the only potentially curative treatment (Capussotti 2011). No other medical intervention concerning CRC liver metastases has yielded the five-year survival rates that have been reported with promising results from early series of up to 58% with surgical liver resection (Abdalla et al 2006, Van Cutsem et al 2010). This is hugely significant since the five-year survival rates for primary bowel cancer, staged at Dukes C with lymph node involvement are within a reach of being comparable, lying at just over 60% (Cancer Research UK Statistics 2019a). Improvements in the treatment of colorectal liver metastases are also set against the context of treatment change for primary bowel cancer and primary cancer in general as outlined in Chapter 1. Cancer Research UK Statistics (2019b) indicate that the five-year survival rates for bowel cancer in general have doubled over the last 40 years. This is partly attributed to improved detection of earlier disease and advances in surgical technique and cytotoxic therapies (Taylor et al 2010). Where liver metastases are concerned, surgical resection is heralded as the gold standard, offering the only optimism for potential cure. This compares favourably with no treatment for colorectal cancer metastases, where original retrospective studies have shown a 2-8% five-year survival rate with a median 6 months survival (Wood et al 1976, Wagner et al 1984) when CRLM are not treated by any treatment modality. It is more difficult to obtain current comparative survival rates today where no active treatment is utilised, given the ethical considerations involved in withholding active treatment options available. Even the advancements made in palliative care, since the late 70s and early 80s have had a direct impact on patient survival with metastatic disease (Gawande 2014b).

A number of factors have helped to bring about more specific improvements in survival associated with liver surgery. One of the main challenges of operating on the liver has been its highly vascular nature, which often accounted for surgically related death or post-

operative complications (Aragon & Solomon 2012). The first liver resection was recorded by Langenbuch in 1886 (Ravikumar et al 1990) and resulted in the patient dying shortly after surgery. Blood loss continued to impede survival until methods to address vascular damage were found. Now, surgical advances in blood sparing techniques and precision liver dissection techniques along with improvements in pre-operative imaging and anaesthetic advances (Chowdhury 2010) have made more liver resections eminently possible with vastly reduced complications and associated mortality. As such, mortality rates have fallen and are now below 1-2% (Capusotti 2015). Also contributing greatly to the attempt to render the liver operable for surgery, has been the role of chemotherapy. Writing in the preface to the surgical textbook Capusotti (2015, p.ix) writes that

> *"the history and evolution of surgery for colorectal liver metastases cannot ignore chemotherapy" (Capusotti 2015, p.ix).*

This highlights the interdependency of different medical disciplines in tackling disease and breeds a new understanding of the need for multidisciplinary working. Advances in the treatment efficacy of chemotherapeutic agents and newer agents such as the use of monocolonal antibiodies e.g. cetuximab also set the context of rapidly evolving treatments which have been responsible for improving outcomes in CRLM resection (Choong & Ammori 2014). This will be looked at in more detail in.

In addition, the role of colorectal cancer follow-up with Carcinoembryonic Antigen (CEA) blood monitoring and combined CT imaging have also played a role in detecting early metastatic disease (Steele et al 2007). Although the consensus remains out on the optimum timeframe for colorectal follow-up or in some cases the value (Jorgenson et al 2015, Makhoul et al 2015), it is likely that without it, the number of cases of liver metastases (and indeed lung metastases and peritoneal metastases) might not be referred at timely intervals to intervening surgical teams for assessment in the detection of first known metastatic disease.

2.3 Colorectal metastases: the biomedical context

Before looking at the current management of CRLM it is worth pausing to consider the biomedical context of colorectal liver metastases in relation to its primary presentation.

2.3.1 Epidemiology of colorectal liver metastases

Recent figures suggest that colorectal cancer is the third most common type of cancer, recorded separately for men and women in the United Kingdom (UK) with approximately

42,000 people diagnosed every year (Cancer Research UK, Statistics 2019b). It is the second most common cause of cancer death contributing to over 16,000 UK deaths per year, as reported by Cancer Research UK, Statistics (2019b). The liver is the most common site for colorectal cancer to spread, second only to lymph node metastases (Simmonds et al 2006). Approximately 20-25% of patients present with liver metastases at the time of their primary diagnosis (Morris et al 2010) and a further 40-50% develop a metachronous liver metastasis following bowel surgery (Stangl et al 2010). With this in mind, approximately 20-25% of patients with CRLM are thought to be candidates for surgical resection (Manfredi et al 2006). Liver metastases are commonly categorised into two groups according to time of presentation; synchronous and metachronous. Synchronous liver metastases are those that are deemed evident within a year of the primary tumour and metachronous metastases present after this period, normally after primary surgical treatment has been completed (Mohammed & Bala 2009). Overall the risk of recurrence is deemed greatest in the first two years following surgery (Metcalfe et al 2004), and therefore the majority of surveillance programmes have been targeted to detect recurrent liver metastases during this time.

2.3.2 Pathophysiology of the liver

The liver is the largest solid organ in the body and is located on the right-hand side of the body lying underneath the right rib cage, as seen in Figure 2.1 of the digestive system. It consists of 2 lobes, the larger right lobe and the smaller left lobe.

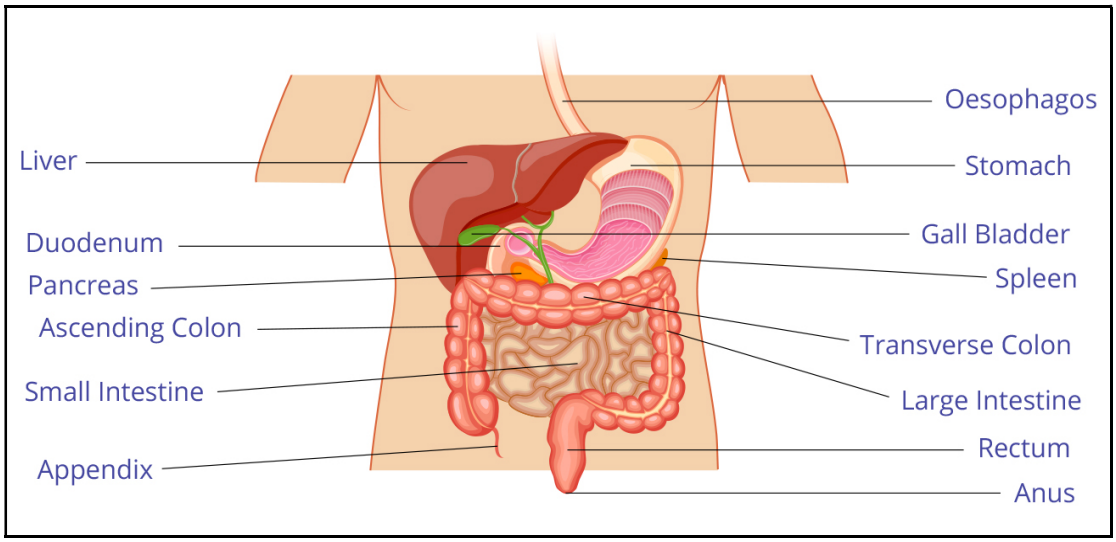


Figure 2.1: The Digestive system.
Source: Home Health UK (2018), Colon/Bowel Cancer https://homehealth-uk.com/coloncancer/

Anatomically, the liver has been divided into sections (see Figure 2.2, overleaf). These sections are labelled as 8 distinct segments; segment 1 is the caudate lobe, segments 2 through 4 form the anatomic left lobe and segments 5–8 form the anatomic right lobe. The segment divisions are based on the direction of the hepatic veins in relation to the intra hepatic distribution of blood through the portal vein. The liver carries out numerous functions which can be categorised into metabolic, storage and secretary functions, having a key role in blood filtration by the absorption of nutrients, production of quick release glucose and fighting infection (Watson 2011). It is unique in that it has two separate sources of blood supply; the hepatic artery which provides oxygenated blood and the hepatic portal vein which carries blood from the intestines and spleen back to the liver to extract nutrients (Bijlani & Manjunatha 2011). It is the shared blood supply of the colon and liver, from the portal vein, which provides an easy transport route for bowel cancer cells to spread and lodge in the liver. It is thought that the mechanism of spread occurs in a stepwise fashion from the portal vein to the liver before spreading to the systemic circulation (Simmonds et al 2006). Therefore, the attraction of treating the liver is clear; if the liver can be effectively treated, the progression of disease spread can be halted, with the outcome of extending life or perhaps, eradication of disease.

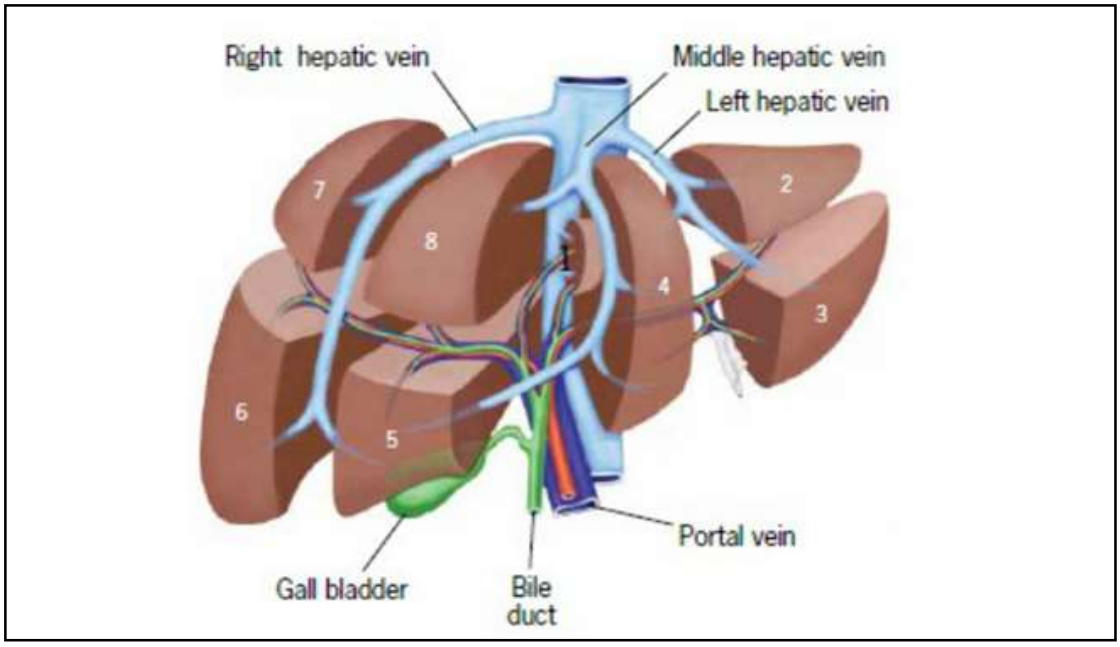


Figure 2.2: Anatomical sections of the liver and liver drainage.
Source: Bowel Cancer Australia (2018), https://www.bowelcanceraustralia.org/liver-metastases

2.4 Key factors in the pathway to colorectal liver resection

A number of factors are integral to obtaining liver resection. These are outlined in the following section.

2.4.1 Multidisciplinary management

Managing the treatment of patients with CRLM is now recommended practice within the context of a multidisciplinary team meeting (MDM) (Scottish Intercollegiate Guidelines Network, (SIGN) 2011, National Institute for Health and Care Excellence (NICE) 2020). The Colorectal MDT initially refers patients to the Hepatobiliary (HPB) MDT for review although referral can go between both MDTs throughout a patient's management of liver metastases in order that appropriate expertise is involved in decision making and planning treatment. The MDTs involve input which integrates surgery and oncology with the support of diagnostic imaging, pathology and specialist nursing input. This is of benefit in considering technical issues of resectability, the role of perioperative chemotherapy in tumour downstaging and in limiting recurrence, tumour features, patient fitness and patient preference. With treatment pathways often taking many months before liver resection takes place, the nurse specialist has an important role to play as a patient's point of contact and advocate in a pathway which has much uncertainty.

Patients with liver metastases are far from a homogenous group but broadly can be categorised into three main groups; those diagnosed with a synchronous liver metastases up to a year from the primary diagnosis, those diagnosed with a metachronous liver metastases on follow-up having had primary bowel surgery and those diagnosed with a further liver metastases having already had liver resection. Appropriate treatment will be dependent upon presentation. A multidisciplinary environment allows for optimal strategic management of these patients, many of whom require complex decision making (Dhir & Sasson 2016, Nathan & Wong 2016). Where liver metastases occur on presentation with the primary tumour, decisions require to be made as to whether to carry out a synchronous or staged resection and in what order. In addition, patients may have other metastatic disease present which can contribute to the complexity of management. Patients developing a liver secondary during follow-up can already have undergone significant treatment. Close multidisciplinary working in order to maintain timely decision making for this group of

patients is crucial and recognises that no one speciality should have dominance in the treatment decision making over another.

2.4.2 Defining resectable disease

Defining resectable disease has proved challenging and is something which has evolved over time. Almost 30 years ago, resectability was defined as less than four metastases, the absence of extrahepatic disease and a resection margin of at least 1cm (Ekberg et al 1986). Liver resections were not recommended unless inclusion criteria were met but over the years, as technological advances have occurred, the criteria have been liberalised. Choong & Ammori (2014) point out that early resectability criteria were based on treatments in the 1980s where poorer imaging and less effective chemotherapy were employed. Currently, resectability is based on the remnant liver rather than on specific inclusion criteria. It is essential to have a sufficient remnant liver volume of more than 20% of the total estimated liver volume, to maintain adequate vascular inflow and outflow and biliary drainage (Pawlik 2007). The overall aim is to remove both macroscopic and microscopic evidence of cancer. A clinical risk score devised by Fong et al (1999) remains one of the most commonly used prognostic scoring methods in this area as referred to in Box 2.1. It is also worth noting that many predictors are not related to the presence of symptoms so it is important that follow-up should contain regular imaging and CEA tumour marker testing.

Predictors of poor outcomes following CRLM resection
- Positive surgical resection margin - Extrahepatic disease - Node positive colorectal cancer - Disease free interval from primary tumour less than 1 year - Multiple liver metastases - CEA more than 200ng/ml following surgery - More than 1 metastatic deposit - Greater than 5cm diameter of any one lesion

Box 2.1: Predictors of poor outcome, CRLM resection
Source: adapted from Fong et al (1999) and Nordlinger et al (1996).

It is likely that as surgical techniques and more effective chemotherapeutic agents are developed that the definition of resectability will continue to expand. Contraindications to liver surgery are more likely to revolve around the future liver remnant, patient co-morbidity and poor functional status (Choong & Ammori 2014). Keeping apace with evolving issues of resectability requires ongoing team communication in order to ensure that appropriate

referrals are made to the hepatobiliary team. In turn, keeping abreast of changing information may also create a significant strain on patients and their families waiting for new communication about their treatment pathway.

2.4.3 Imaging in the management of colorectal liver metastases

A diagnosis of CRLM is made by appropriate imaging such as computerised tomography scan (CT), magnetic resonance imaging (MRI), positron emission tomography-computed tomography (PET-CT) or ultrasound. Histological confirmation is not recommended as there is some evidence that a liver biopsy can result in poorer outcome after liver resection due to possible disease tracking and spread via biopsy needle (Garden et al 2006). Initial staging by way of a CT scan of chest, abdomen and pelvis may suggest presence of liver metastases. An MRI will provide further detail on anatomical positioning of liver metastases.

A PET-CT will rule out or confirm presence of additional sites of secondary spread, by detecting radiation from a radiotracer called fluorodeoxyglucose (FDG) which is similar to naturally occurring glucose in the body (NHS UK 2018, https://www.nhs.uk/conditions/pet-scan/). Analysing build-up of this glucose solution determines how well certain organs are performing and how likely secondary spread is to those organs that highlight as having more glucose uptake. Just over a decade ago, all patients had to travel to Basingstoke from Scotland for a PET facility. At the time of writing, there are now four major centres with patient PET facilities in Scotland, but image reporting and cost of running is both costly. Interestingly, a randomised controlled trial reported by Moulton et al (2014) has questioned the value in PET-CT in addition to CT alone. The trial, which randomised patients to either PET-CT or CT alone prior to hepatic resection for CRLM did not result in frequent changes in decision making across the groups of patients which may suggest that CT alone can determine decision making in this setting with a cost reduction in imaging. It is worth noting that additional secondary sites of metastatic disease detected through imaging will not necessarily exclude a patient from CRLM as these sites may be considered amenable to further resection, e.g. lung. Cases with extra-hepatic metastases need to be considered on an individual basis (Choong & Ammori 2014) and increasingly demonstrate the advancement in surgical resection of metastases located at different sites.

A particular challenge in the area of imaging is the issue of disappearing liver metastases following pre-operative chemotherapy. Disappearing liver metastases refers to the complete

response or disappearance of liver metastases following preoperative chemotherapy and can occur in up to a quarter of patients who undergo chemotherapy in either a neoadjuvant setting for resectable liver metastases or as a conversion therapy for unresectable metastases (Kassahun 2015, Dhir & Sasson 2016). Kassahun points out that although the beneficial effect of liver resection on survival is clear, the extent to which liver disesase is resectable when not easily seen on imaging, has not yet been established. This can make it particularly challenging for surgeons to resect. It may also prove a particularly challenging aspect to communicate to patients, with the potential for accompanying emotional burden, adding in an additional level of uncertainty amid the process of waiting.

2.5 Treatment of resectable colorectal liver metastases

As outlined in section 2.4.1., the overall treatment of CRLM requires a multidisciplinary approach. Yet, the overall treatment of CRLM is not an exact science, and this can best be understood through stage at disease presentation and whether liver metastases present with a synchronous bowel primary or as a metachronous finding during a period of follow-up. In addition, this can highlight some of the uncertainties surrounding treatment.

2.5.1 Order of treatment in synchronous presentation of CRLM

The order of resecting synchronous CRLM remains controversial and is well debated in the literature (Choong & Ammori 2014, Collins & Chua 2017). There is little definitive evidence to support whether resection of the bowel primary should occur prior to liver metastases resection or whether both primary and liver metastases can be resected simultaneously. Retrospective reviews of caseloads have shown simultaneous resection to be safe and should be considered where the location of the tumour is amenable to a simultaneous resection and where joint expertise from a bowel and hepatobiliary surgeon can be co-ordinated (Martin et al 2003, Chu et al 2004). Certainly, clinical presentation may guide the decision to operate on the primary tumour first if a patient presents with obstruction, bleeding or perforation (Mohammed & Bala 2009). Where simultaneous resection cannot be performed, multidisciplinary clinical judgement is important to consider cases on an individual basis with the overall aim of resulting in complete resection of both the primary and metastatic liver site.

2.5.2 The role of systemic anti-cancer therapy (SACT)

The term systemic anti-cancer therapy or SACT, has come to denote the move away from chemotherapy solely being utilised as a systemic cancer therapy and encapsulates the use of other systemic and newer targeted therapies or biologic therapies, such as monoclonal antibodies and immunotherapies. Newer forms of systemic treatment may complement conventional chemotherapy or in some cancer treatment regimens may replace them. In CRLM management both chemotherapy and more recently, monoclonal antibodies are utilised.

The purpose of chemotherapy in the context of CRLM resection is either to improve long term survival following liver resection or to facilitate liver resection in those patients who are considered to have borderline resectable disease or non-resectable CRLM. The greatest evidence for using chemotherapy in combination with surgery stems from the European Organisation for Research and Treatment of Cancer, (EORTC), randomised trial using FOLFOX (5FU/ leucovorin/oxaliplatin) chemotherapy perioperatively with surgery against surgery alone (Nordlinger et al 2008). The results showed a 7-8% improvement in 3-year progression-free survival in those patients who received perioperative chemotherapy, to approximately 35%, compared to resection alone at 28% (Nordlinger et al 2008). As such chemotherapy is used more often prior to liver surgery rather than following liver resection in order to reduce likelihood of recurrence (Ismaili 2011, Wang & Li 2012). A standard regime of neoadjuvant FOLFOX or CAPOX (capecitabine and oxaliplatin) may last for 6 cycles (approximately 3-4 months) (Brandi et al 2016). For the individual with liver metastases, length of SACT treatment has a likely additional psychological burden when the desire is to achieve liver resection, and certain scenarios can significantly extend the pathway. For example, for some patients presenting with a synchronous liver metastases and rectal primary, where the liver may be considered as borderline for resection, the length of time to liver resection may take 12-18 months. In such cases, overall treatment may invovle down-staging primary radiation with chemotherapy followed by primary surgery and use of chemotherapy plus or minus a targeted therapy, in order to attempt to convert liver disease resectable.

Chemotherapy may be considered following liver surgery depending on pathology or particularly if a patient did not receive chemotherapy perioperatively (Wang & Li 2012). There is also increasing evidence to say that where patients have borderline resectability, a combination of oxaliplatin (or irinotecan) and 5-FU/leucvovorin chemotherapy can be used

as a downstaging agent to convert unresectable disease to resectable (Wang & Li 2012). In some cases perioperative chemotherapy is best avoided if a patient has had recent chemotherapy (usually within 2 years) or has evidence of a fatty liver (Ismaili 2013). In such cases there is greater likelihood of causing damage to the liver and creating post-op surgical complications. Chemotherapy in general is associated with injury to liver parenchyma with oxaliplatin and irinotecan both responsible for causing steatosis and steatohepatitis (Passot et al 2016). Steatosis can increase blood loss after hepatectomy and steatohepatitis can impair liver regeneration. Careful pre-assessment of the liver can help to determine impact of chemotherapy when used pre-operatively and leaving at least 5 weeks between chemotherapy and liver resection can reduce liver injury (Passot et al 2016).

Recently the use of monoclonal antibodies, such as cetuximab have provided further benefit in helping convert unresectable disease to resectable (Cooper & Curley 2013). Cetuximab is a targeted therapy that targets and binds to the epidermal growth factor receptors (EGFR) on cells. Cetuximab works by binding to EGFR on cancer cells which in turn blocks epidermal growth factor, to prevent cancer cell division and further regrowth (see Figure 2.3). In this way it both blocks the signal for cell division and triggers an immune response from the individual. Common side effects are an acne like rash, which is commonly evident 2 weeks after starting treatment, skin fissures, nail changes and gastrointestinal effects such as nausea (Macmillan Cancer Support 2018, Petreilli et al 2018).

Cetuximab is deemed suitable for those with bowel cancer who express a wild-type KRAS gene which is the non-mutated gene (Ismaili 2011). RAS mutations occur in approximately 45% colorectal cancers (Cercek et al 2017). The clinical implication of this is that patients with metastatic colorectal cancer who are being considered for cetuximab should be tested for the presence of a KRAS mutation prior to therapy. It is also deemed more effective for left sided tumours than right sided, although the mechanism for this is not clear (Goldberg et al 2018).

The most convincing evidence for improved response rates in first line metastatic colorectal cancer with cetuximab and chemotherapy comes from the CRYSTAL study (van Cutsem et al 2011) and the COIN trial (Maughan et al 2011). The CRYSTAL study found prolonged overall and progression free survival with KRAS wild type tumours receiving cetuximab in combination with 5FU/leucovorin/irinotecan (van Cutsem et al 2011). While the COIN trial

did not show any benefit to either overall or progression free survival, it did show increased response to cetuximab in combination with capecitabine/oxaliplatin (CAPOX) or 5FU/leucovorin/irinotecan (FOLFIRI) (Maughan et al 2011). Again of note, both treatment regimens have a specific side effect profile, with more commonly experienced side effects of CAPOX including skin redness (palmar plantar syndrome), peripheral neuropathy and gastrointestinal effects such as nausea, sore mouth and diarrhoea (Macmillan Cancer Support 2018b). FOLFIRI's common side effect profile also includes gastrointestinal effects of nausea, diarrhoea and sore mouth and will cause hair loss (Macmillan Cancer Support 2018c). Understanding the side effect profile helps to understand the overall context of what patients are likely to encounter through the active process of being considered for CRLM resection in order to address quality of life issues during treatment.

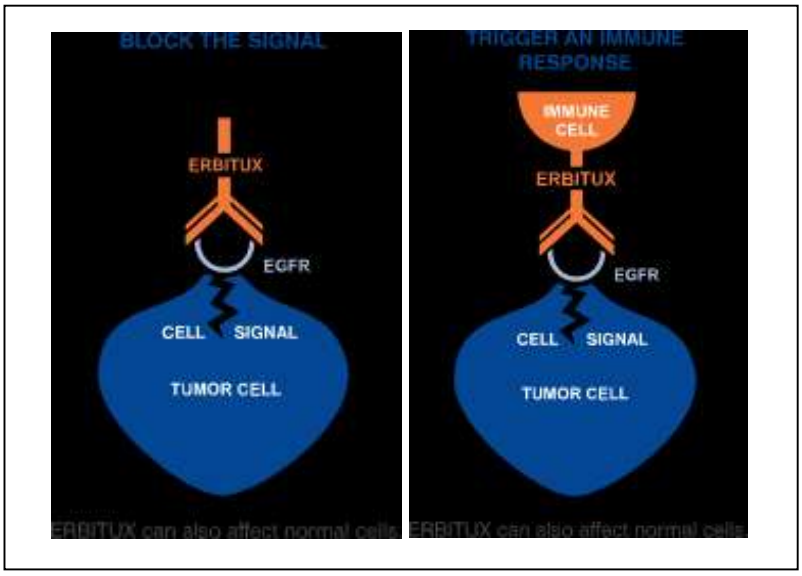


Figure 2.3: Mechanism of cetuximab
Source: Lilly (2019), https://www.erbitux.com/understand-erbitux/mcrc.html

Cetuximab is available for restricted use within the United Kingdom and has had varied adoption across the U.K. to the current recommendation. The recommendation for widened use was made first in Scotland in 2015. As of January 2015, The Scottish Medicines Consortium (SMC) accepted cetuximab under the following restriction,

> *"For use in patients with RAS wild-type metastatic colorectal cancer, in combination with irinotecan or oxaliplatin-based chemotherapy, in patients who have not previously received chemotherapy for their metastatic disease (first-line treatment)." (SMC 2018, para.1).*

This was a widening of the previous restriction, implemented in 2010, whereby it was indicated for use in liver only metastases that were considered non-resectable but that may be amenable to potentially curative surgery following chemotherapy and cetuximab (SMC 2014). The new EPOC trial aimed to determine if the addition of monoclonal antibody therapy was of value in the neoadjuvant setting by randomising standard based chemotherapy (FOLOX or FOLFIRI) plus or minus cetuximab (Primrose et al 2014). After all, having already established the role of chemotherapy in the perioperative setting for CRLM, it seemed logical to proceed to the next step and ask whether outcomes could further be improved by combining biologic and cytotoxic agents (Nordlinger et al 2015).

Surprisingly, an early review of the study at the end of 2012 showed a significant reduction in survival in the arm having chemotherapy and cetuximab which led to the trial being closed early for safety. Progression free survival was 13.6 mths vs 6.2 on the cetuximab arm and and likewise overall survival was 29.1 months vs 22.7 mths. Primrose and colleagues concluded that cetuximab could not be recommended for use in the neoadjuvant setting, suggesting that cetuximab may cause some molecular interaction that required further examination. The results were highly contentious, going against previous studies that had shown improvement in survival with cetuximab. The trial was criticised from a number of angles including taking RAS mutant expressing individuals into the study sample, poor study powering and difficulty modulating surgical variance across the U.K centres (Nordlinger et al 2014). The results have been considered with caution, only prompting the need for further studies with the use of biologics and chemotherapy. Due to the concerns over study design and interpretation, the new EPOC study alone has not changed the recommendation that cetuximab can be used in first line treatment of metastatic colon cancer alongside conventional chemotherapy including oxaliplatin or irinotecan agents. Cetuximab's incorporation into the management of metastatic colon cancer has contributed significantly to the treatment landscape of CRLM.

2.6 Techniques to improve success of liver resection

A number of techniques have helped to improve the success of liver resection and thereby leave a sufficient functioning liver remnant. These key techniques are mentioned as part of understanding the overall process that can extend the liver pathway for patients.

2.6.1 Portal vein embolisation

Treatment advances have also led to novel approaches which can improve the resectability and outcomes of colorectal liver resection. Portal vein embolisation (PVE) uses the regenerative properties of the liver by redirecting portal blood supply to segments of the future liver remnant, which causes liver hypertrophy (Mohammed & Bala 2009). It is only indicated when the future liver remnant is considered too small to maintain function. Use of PVE has been associated with a reduced postoperative morbidity and an increase in the number of patients eligible for curative resection (May & Madoff 2012).

2.6.2 Ablative techniques

Ablative techniques such as Radiofrequency Ablation (RFA) or microwave ablation are also used to increase resectability by way of using heat energy to destroy cancer cells (Mohammed & Bala 2009). RFA is more commonly used and can be used more than once where indicated. A radiologist uses an electrode probe to apply an electrical current to a tumour. The current heats the cancer cells to a high temperature resulting in ablation and cell death. This can be done prior to liver resection in combination with the surgery to improve surgical outcome. Generally those lesions which measure 3cm or less and those which do not lie adjacent to major vascular structures are more amenable to RFA (Choong & Ammori 2014). Cryotherapy, involving the delivery of subzero temperatures to the liver via probes during surgery is used infrequently due to lack of evidence of therapeutic benefit (Macedo & Makarawo 2014). While some ablative techniques can be used as an adjunct to surgery, wide variation in outcome has been reported with insufficient evidence that ablative techniques could be used as a 'stand alone' treatment for liver metastases. As such the American Society of Clinical Oncology (ASCO) had recommended that international centres do not use ablation to treat liver metastases alone but continue to recommend liver resection as the gold standard of treatment (Wong et al 2010).

2.6.3 Two staged liver resections

A further way to increase resectability is by carrying out two staged liver resections. One such method of a staged liver resection that is increasingly considered is a technique called ALPPS (Associating Liver Partition and Portal vein Ligation for Staged hepatectomy) (Donati et al 2013). This technique utilises the regenerative abilities of the liver by allowing regrowth of the future liver remnant in between two liver operations. A staged hepatectomy is

particularly used in patients with extensive bilobar disease where the first liver operation plus or minus ablation would not yield a sufficient liver remnant (Choong & Ammori 2014). The least affected lobe of liver is generally operated on first to allow regeneration and further resection with the aim of clearing remaining disease in the second operation. Furthermore, in some cases, where recurrence occurs again in the liver, it is possible to continue to a re-resection 2 or 3 times with curative intent (Cooper & Curly 2013). All cases are to be considered individually, carefully evaluating risk and benefit to a patient alongside their preferences for treatment approach (Nathan & Wong 2016).

2.7 Surgical considerations in CRLM

A number of aspects are of worth considering which are relevant to the current picture of colorectal liver resection. These are referred to in turn.

2.7.1 Surgical developments

The inherent characteristic of liver regeneration makes the liver amenable to surgery. However, the main problem has been the highly vascular nature of the liver so techniques which help to minimise blood loss are favoured. The traditional 'clamp crushing' technique to dissect hepatic parenchyma was compared with three newer innovations (the ultrasonic aspirating dissector, the Hydrojet and the dissecting sealer using radiofrequency ablation in a randomised controlled trial (Lesurtel et al 2005) and later in a Cochrane review (Gurusamy et al 2009). Little difference was demonstrated across the techniques but the traditional clamp crushing technique which is significantly cheaper was associated with faster tissue transection at surgery and lower transfusion requirements, therefore newer transection techniques have not been advocated in standard practice.

There are no randomised trials in the use of laparoscopic surgery in CRLM, yet the review of retrospective series (Simillis et al 2007) has found laparoscopic hepatectomy to reduce blood loss and duration of hospital stay with oncological clearance similar to that for open hepatectomy. In 2008, Buell et al (2009) deemed laparoscopic colorectal liver resection to be safe and effective for properly trained surgeons. Patients with limited tumour burden (2 or fewer metastases)and those with small tumours in the left lateral segments of the liver have been reported as more suitable to laparoscopic surgery whereas those patients with tumours involving the inferior vena cava, portal veins or patients with multifocal or bilobar

metastases are best served with open surgery (Xie et al 2016). As with primary colorectal surgery, patient selection for laparoscopic surgery is crucial for safety and outcome.

2.7.2 Outcome and recurrence following surgery

In the absence of randomised controlled trials comparing colorectal liver surgery with other treatment options, it is difficult to ascertain the benefits of CRLM. Nevertheless, 5-year survival rates range between 40-60% and one fifth of patients may achieve survival of 10 years or more (Nathan & Wong 2016). Complications of liver surgery can include infections, biliary and vascular complications and liver failure but the incidence is low and liver resection is also deemed safe for patients over 70 years with appropriate selection (Di Benedetto et al 2011). Approximately two-thirds of patients later develop a recurrent tumour, and half of them have a recurrent tumour in the liver (de Liguori-Carino 2008). In addition, a R1 resection (positive margin), while generally depicting worse disease behaviour, is not show to be related to overall survival when compared with R0 resections (Pencovich et al 2019).

Several prognostic scores exist to predict a patient's risk of recurrence and chances of long-term survival on the basis of preoperatively measured parameters. The three most commonly used scoring systems in hepatic surgery are those of Nordlinger, Fong, and Iwatsuki (Kolev et al 2014). Essentially a low score equates to a lower risk of recurrence and overall survival. As yet, there are no preoperatively prognostic tools which can accurately identify patients who will not benefit from surgical treatment. Of relevance to add is that a number of patients already having had colorectal surgery will have residual effects of multimodal therapy for a colorectal primary. There is a growing body of evidence for the late term effects of multimodal therapy in the pelvis, particularly those located lower in the bowel in the rectum and sigmoid (Knowles et al 2013, van Heinsbergen 2018). This is of worth considering when one understands the long and complex journey many will have gone through before being considered for colorectal liver resection.

2.7.3 Main controversies in colorectal liver resection

Kassahun (2015) has collated the main unresolved areas in the management of colorectal cancer liver metastases existing around four central controversies; (1) the simultaneous approach for synchronous liver resection, (2) the use of pre-operative chemotherapy, (3) resection extent for disappearing liver metastases and (4) the sequencing of liver resection. The arguments for and against were summarised in a table in this paper and have been

included Table 2.1 overleaf. The table provides a comprehensive overview of the arguments in the four main unresolved issues which have been highlighted in this chapter. Given the lack of evidence by way of randomised trials, it is perhaps understandable how the arguments differ. With differing of opinion at times among clinicians as to the rationale behind decisions, the importance of decision making through multidisciplinary team meeting comes into play so that decisions are made on an individual patient basis, according to staging, tumour and fitness for treatment. However, with the complexity conveyed in some of these arguments, it is worth stressing that this complexity is the same backdrop to which treatment decisions are shared with and conveyed to patients. With this knowledge in mind, informing some of this complexity may prove challenging.

2.8 Implications for future patient outcomes

A recent study by Rees et al (2014) using the quantitative quality of life tools with 232 patients diagnosed between 2004-2007 have shown excellent quality of life, high levels of function and few symptoms at 1 year following CRLM resection. While no studies currently give patient reported outcomes longer than 1 year, it may be reasonable to assume that patients remaining disease free could expect a favourable quality of life similar to that reported by long term survivors of breast cancer (Hsu et al 2013). Survival from treatable metastatic colorectal cancer is not, as yet, akin to that of metastatic breast cancer, where survivors can live in excess of a decade. However, the treatment advances made in this area are extending the boundaries of what was commonly expected for a diagnosis of CRLM and creating a new category of metastatic disease. This has an impact on how patients experience their treatment pathway, follow-up and ongoing survivorship needs.

It is not surprising that where improved outcomes are concerned, much of the literature has focused on treatment efficacy and technique. There is a deficit of research which explores patients' needs or experience of having undergone consideration for hepatic resection. Not all patients considered for liver resection will proceed to surgery and therefore the pathway can be punctuated with additional uncertainty. Patients can experience the tension of knowing that their cancer has spread whilst maintaining the hope for containment or even potential cure.

Treatment strategy	Arguments in support of	Arguments against
The simultaneous approach	No increase of morbidity and/or mortality in carefully selected patients Removal of all cancer in a single procedure; reduces disease dissemination Similar PFS and OS compared to those with staged resection	Considerable increase of morbidity and or/mortality May result in unnecessary liver resection in rapidly progressing disease Higher recurrence. Negative impact on long term outcome
Pre HR chemotherapy	Decreases resection magnitude Eradicate micrometastases Increases R0 resection rates Assesses responsiveness to specific chemotherapy thus identifying and selecting patients with favourable tumour biology. Improves PFS.	Delays liver resection. May result in a unresectable state in non-responders May lead to liver parenchyma damage and increased postoperative morbidity No impact on PFS and OS
Extensive resection for DLM	Response on imaging does not necessarily signify clinical or pathological response (in up to 83% evidence of residual disease); so resect all initial sites if possible, despite disappearance on imaging	As durable clinical response is as high as 62%, resect only residual macroscopic disease leaving the disappeared lesions in situ, continue systemic chemotherapy alone
The liver-first approach	It is the liver metastasis rather than the primary tumour that gives rise to systemic metastatic disease, so it should be addressed first It avoids the risk for progression of CRLM while the patient is treated for the primary tumour, especially if complications are encountered; thereby improving median survival and 3-year survival Option to give systemic chemotherapy as a first step early in the treatment course that may lead to an effective response in the primary tumour and avoids resection	No, it is the primary tumour that produces systemic effects promoting angiogenesis in the liver, thus favouring the spread of metastatic disease Despite apparently similar treatment protocols in those few studies, the variations in survival rates of the liver-first approach are wide; so its comparison with the bowel-first approach or the combined strategy is problematic

Table 2.1: Summarised key controversies surrounding the management of colorectal cancer liver metastases. (Adapted from Kassahun, 2015).

Terminology key; CRLM, colorectal liver metastases; DLM, disappearing (no longer visible on imaging) liver metastases; HR, hepatic resection, PFS, progression free survival; OS, overall survival; Pre-HR chemotherapy, neoadjuvant chemotherapy for resectable CRLM

Observationally as health professionals looking on, it can be seen that the pathway holds much anxiety for patients and families. Often the treatment teams involved are located at different hospital sites and this may add further complexity for some patients when seeking to convey information at timely intervals. Additionally, this study takes place in the context of the busy clinical practice involved with the treatment management of both primary and secondary bowel cancer (see Appendix I). As treatment pathways become more individualised and perhaps more complex, the need for a point of contact across the pathway is realised. Nurse specialists can work with patients to convey information across the pathway at relevant time points, manage expectations of timescales, tailor specific information needs, manage physical and side effects of systemic therapy and the liver resection and can help with goal setting, an important element of hope (Snyder 2000). However, with little evidence from the literature to reflect this or how the needs of such patients can best be met, it is difficult to rely on purely observational data.

2.9 Chapter summary

Advances in imaging, surgical technique and systemic therapies have led to exciting developments in the management of operable metastatic colorectal cancer with encouraging five-year survival rates (Rees et al 2014). Patients undergoing CRLM resection represent an increasing patient population where surgery can be utilised in managing secondary cancer. Consequently, this new picture of treatment requires a reconsideration of what we have conventionally understood by metastatic disease as discussed in Chapter 1 (1.3), 'Growing a new concept of metastatic disease'. While multimodal therapy has given cause to expand our understanding of metastatic disease in colorectal liver metastases, the combination of surgery and systemic anti-cancer therapy can make for a prolonged pathway of treatment and can have additional burden of recovery and residual side effects. Although it is recognised that the pathway to liver resection is often complex and emotionally demanding, little is known of the reality of being considered for colorectal liver metastases resection from the patient's perspective. The next chapter will consider the impact of liver resection on the patient by drawing on associated and comparable literature. Further research with this group of patients has value in seeking to improve the experience of the surgical pathway to liver resection and thus direct nursing intervention where it has most benefit.

Chapter 3

A change of lens: from technical possibilities to patient perspective

"We see the world through the lens of all our experiences; that is a fundamental part of the human condition" (Madeleine M Kunin, 2009, para.5).

3.1 Chapter overview

In 1962, scientific philosopher, Thomas Kuhn published perhaps one of the most influential philosophical texts of the twentieth century, '*The Structure of Scientific Revolutions*, in which he challenged traditional thinking on how humankind orders scientific progress and therefore understands the world. Kuhn's version of how science develops departs dramatically from positivist theories of a continual building upon of unshakeable knowledge to instead seeing scientific progress develop from changing intellectual circumstances and possibilities (Kuhn 2012). In this way progress reflects change that encompasses discontinuities in understanding and alternates between 'normal' steady progress and 'revolutionary' phases where communities of specialists enter periods of turmoil, uncertainty and angst in their thinking (Naughton, 2012). The result of this is a change in the old paradigm of thinking to a new one which becomes accepted and the previous paradigm becomes deficient, representing a paradigm shift, a phase which is also familiar to us in modern day parlance. Kuhn understood that theoretical commitments between two scientists can influence how theories and knowledge are viewed.

Interestingly, Kuhn's argument was based upon the psychology of vision whereby the use of special goggles, can invert the world as upside down on the retina. Continual use of such googles will allow for compensation and resultant movement but when the goggles are removed, the view of the world initially seems displaced. Kuhn embraced the idea that how we view things alters over the course of our lives and as a result of exposure to experiences. This idea is also echoed in the opening quotation for this chapter by former American diplomat, Madeline Kunin, albeit from a socio-political viewpoint. In a similar way, our concept of how we view and what we expect from medicine has changed. The last 50 years, in particular, have borne witness to incredible changes in the treatment of diseases such as tuberculosis and in improving survival in many of the common cancers (McKie 2015). With such progress, we could be forgiven for thinking that developments in medicine will continue

at this pace. It is certainly encouraging to see how advances are beginning to challenge the idea that a diagnosis of cancer does not unequivocally equal a death sentence as conventionally viewed (Diamond 1999). Some treatment possibilities have given shape to a reality and pave the way to change a collective perspective about cancer across society and indeed our perspective of a diagnosis of metastatic cancer, most notably breast cancer (Sledge 2016).

This chapter will turn to look at a different perspective; that of the patient. Yet, qualitative studies dirctly related to colorectal liver metastase are limited. The few that have been published, will be discussed in more detail before drawing in other qualitative research that has a bearing on CRLM, including a number of phenomenological studies relating to surgery for primary colorectal cancer. The content will then perhaps take a more surprising turn to look at literature in the area of liver transplant, which arguably may provide a parallel experience to CRLM. This was an area which came as an exciting and plausible consideration when reviewing the literature.

3.2 Identification of literature

Undoubtedly, Chapter 2 has highlighted that there is often a lack of consensus about the management of colorectal liver metastases. As in any area of healthcare, developments are always confined by what is technically possible and also, correctly, ethically plausible. While much of accepted practice in the treatment of CRLM has not been adopted by conducting randomised controlled trials, advances contributing to surgical technique, imaging and systemic anti-cancer treatments have pushed some of the boundaries in CRLM which in turn has broadened our understanding of what we once thought possible in the treatment of metastatic disease. The developments are perhaps somewhat of a parallel to the traditional route of science as described by Kuhn (2012). In this environment, there is considerable capacity for asking new questions and trying new methods of treatment in an attempt for progress in the overall management of colorectal liver metastases. As indicated by Kuhn, many revolutions of theory may be required in a bid to move understanding along. The medical literature in colorectal liver metastases (CRLM) has naturally centred around principles of delivery, efficacy and safety, sharing the technical viewpoint from the clinician's perspective. However, what of the view from a different lens; what of the patient's perspective that is of those on the receiving side of being considered for CRLM resection?

To this end, literature searches and an alert notification system (2000 onwards) were established using the databases, CINAHL, EMBASE, MEDLINE, the COCHRANE LIBRARY and DISCOVER ED (University of Edinburgh database). Combinations of the words, 'experience', 'qualitative', 'phenomenology' 'liver metastases', liver secondary', 'liver resection', 'pathway' and 'journey' were used. Reading was not limited to these searches but acted as a springboard to other areas of reading. Whereas management of uncertainty is well documented in the literature, as evidenced in chapter 2, there is a deficit of qualitative research in this area for those having, or being considered, for surgical resection of colorectal liver metastases. This was very much the position at the conception of this study and remains the case.

Where there is a limited literature base, it is often challenging firstly, to identify a suitably comparable area of literature and, secondly, to know where to discontinue the search appropriately. I was aware of the qualitative literature on living and dying with colorectal cancer but it was clear from the outset that resection of colorectal liver metastases with favourable five year survival rates, did not sit well within a palliative context as referenced in Chapter 1 and Chapter 2. My clinical experience also bore witness to this, thus preventing me from aligning liver resection to end of life literature. On reflection, I note there may be some relevance to the literature on the fear of recurrence but this was not included in the literature search at the outset as many participants already came to the study with recurrence as a starting point. As such, this research did not have the scope to look specifically at the issues around recurrence but rather the focus was on the process of being considered for CRLM and the pathway itself. Figure 3.1, overleaf, outlines the literature search. The Critical Appraisal Skills Programme (CASP) criteria (https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf) provided a useful tool in appraising the research literature. The ten questions on the qualitative checklist allowed study rigour, credibility and trustworthiness to be constructively appraised for inclusion.

The key literature in this Chapter and in Chapter 4 drew firstly on phenomenological studies, directly related to the use of surgery in colorectal liver metastases, before incorporating phenomenological colorectal cancer or other related qualitative cancer literature. It is recognised that many studies were excluded at this point but another researcher may have

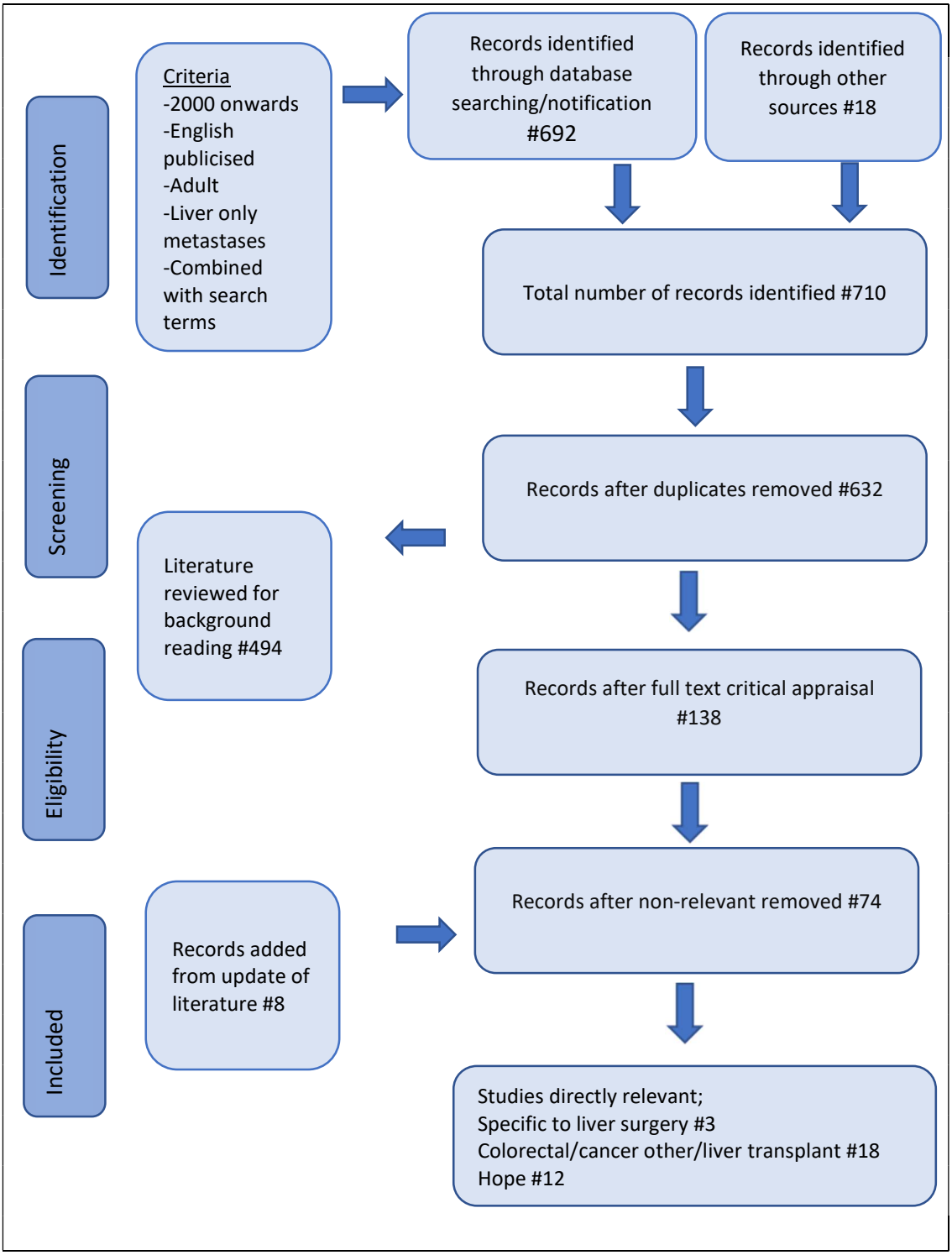


Figure 3.1: PRISMA flow diagram showing strategy for literature inclusion

drawn relevance from them. The parallel literature that I saw best fitting to the CRLM pathway experience did not necessarily sit best with colorectal cancer per se or other related cancer experiences but on review of the literature, I was drawn to phenomenological literature on the experience of waiting for a liver transplant. Discussion with the

Hepatobiliary team from observations within their practice, reaffirmed the relevance of drawing upon this literature for the comparison it drew with liver related surgery, waiting and uncertainty over a significant time period. The extension of the literature into hope in the following chapter arose from the links with uncertainty and waiting for this population and the focus that maintaining hope amidst a complex surgical pathway had for patients with colorectal liver metastases.

At the outset, the study always had a service development outcome in mind, with the mainstay of study funding reflecting this intention. Relevant patient experience literature to support the study application was limited. It was only later with the study commencing, that the first and, as yet, only phenomenological account of patients having undergone liver resection was published in 2009 by American authors McCahill & Hamel-Bisssell in the Journal of Supportive Palliative Care. This work was not known about when selecting study design and methodology so had no influence on this current study. Yet, as this is the only published study, it remains the main reference point of directly relevant literature and will be discussed in section 3.2. Further review of literature yielded two other studies as relevant to patient experience in surgery for liver metastases. While neither may be perhaps seen as a best fit, their place in section 3.2 is justified as they directly relate to the use of major surgical intervention for CRLM. An overview of the main three studies are included in Table 3.1. The second study is a Norwegian study by Vidnes et al (2013) and interestingly reports on the more experimental use of liver transplant surgery for treating CRLM. It has been included as it reports on the use of radical surgery for CRLM and there may be some useful considerations. A quantitative quality of life search was also undertaken as part of this study and referred to in section 3.2. The third study was undertaken as a doctorate in Health Psychology by Whale (2016) and reported on the findings of qualitative interviews conducted with a selection of patients who had been part of a previous study cohort assessing the use of the European Organisation for Research and Treatment of Cancer Core Quality of Life (EORTC QLQ-C30) and colorectal cancer liver metastasis specific module (EORTC QLQ-LMC21).

Outside of these studies included in Section 3.2. and in the absence of directly comparable studies, one of the challenges has been how far to widen the net in order to draw on other studies which may have relevance to the CRLM study group. The next obvious search extension to look for qualitative literature is the use of surgery in other areas of colorectal

metastatic surgery, such as lung resection or peritoneal resection which have been referred to in Chapter 2. Searches yielded nothing for this and likewise there was no published qualitative work in the use of surgery for metastases in other cancer types. The absence of qualitative work in metastatic cancer surgery then becomes a feature in itself and additional sources of reference require to be drawn on for consideration.

3.3 Colorectal liver metastases surgery from the patient's perspective

Patients with liver metastases are far from a homogenous group but broadly can be categorised into three main groups; those diagnosed with a synchronous liver metastases at the same time of their bowel primary, those diagnosed on follow-up having had primary bowel surgery and those diagnosed with a further liver metastases having already had liver resection. Where liver metastases have been diagnosed at the same time as the primary tumour, patient assessment is necessary in order to ascertain if both tumours can be resected under a synchronous resection or a staged resection. If a staged resection of primary bowel tumour and liver metastases is to be carried out, the order of tumour resection will need to be assessed in order to maximise the feasibility of removing both tumours and to maximise the overall patient outcome in both survival and reduction of tumour (Kassahun 2015, Wang et al 2016). Patients developing a liver secondary during follow-up may already have undergone significant treatment. In addition, patients may have evidence of other metastatic disease, e.g. lung metastases, either diagnosed at the outset of original bowel primary or during follow-up. This can add to the complexity of management as discussed in chapter 2. Close multidisciplinary working in order to maintain timely decision making for this group of patients is crucial (SIGN 2011, NICE 2020).

The 'typical' pathway for cancer treatment is often likened to somewhat of a rollercoaster journey (Fawcett 2011) with emotional and physical setbacks accounting for some of the journey lows and the success of treatment or resolution of symptoms equating to feelings of relief experienced on the peaks or highs of the journey. This may be exemplified in the pathway to hepatic resection for colorectal liver metastases, where patients may be overwhelmed with the knowledge that their cancer has spread beyond that of the primary bowel site while at the same time holding the additional burden of whether or not they are eligible for surgical resection (Chiappa et al 2009). Where liver metastases are resectable, a typical pathway to liver resection, where neo-adjuvant cytotoxic therapy is not advocated,

can take approximately 2-3 months and where neo-adjuvant cytotoxic therapy is advocated can take approximately 6 months (local data). In more complex cases, where liver metastases are deemed to have borderline liver resectability and present alongside a bowel primary also requiring resection, the length of wait before a decision is made regarding a liver resection can exceed a year. This may be especially the case for those with a rectal tumour requiring downstaging radiation and surgery to treat the rectal primary (local data). With these scenarios in mind, it must be recognised that there can be a significant wait for patients living with the hope of a liver resection but also with the fear that the disease may grow and rule out the possibility of liver surgery.

Perhaps it is not surprising that there is a deficit of publications which survey patients' needs or experience, since colorectal liver resection has grown from a base in palliative surgery. As such there is much emphasis on improved survival, and so that may be why much of the hepatic resection literature focuses on treatment efficacy and surgical outcome. It can be argued that only when a procedure has gathered momentum as standard practice (and often in the absence of randomised controlled trials), does the perspective and experience of the participant come into the fore. Reed et al (2009) report that there has been difficulty recruiting patients with metastatic disease to studies because of the nature of their disease. However, one could expect that recruitment to studies for metastatic disease will improve as standard treatment options continue to improve survival. For those who develop liver metastases growth of disease bulk is slow when compared with metastatic disease in other cancer types, (e.g. lung, pancreatic) and it is therefore conceivable that patients who are actively treated for CRLM are in a position to be invited to take part in phenomenological studies in order to open up their experience, which in turn may be used by health professionals to make improvements to care. It is likely that as treatment options for metastatic cancer types improve, so too will patient recruitment for qualitative studies.

3.3.1 Patient experience of colorectal liver metastases resection

As set out above, there is only one American study by McCahill & Hamel-Bissell (2009) which report the experiences of patients who had undergone resection for colorectal liver metastases, primarily around the area of treatment decision making. Published in 2009, in a non-mainstream oncology journal, with only an impact factor of 1.199, the study serves as something of a marker in time evidencing the cusp of cultural treatment changes in metastatic colorectal cancer. This can be seen as the study was conducted between 2005

and 2006 but includes participants who have had surgery and or ablation for CRLM between 2003 and 2006, at a time when surgery was becoming more conventionally used in the management of CRLM. Study characteristics can be viewed in Table 3.1 below.

The study reflects a change in optimism at a time when boundaries of colorectal cancer management were being extended from that of purely palliative management to using surgery to treat liver metastases more aggressively with the aim of control and the potential for cure. This study is clear in its aim in seeking to identify common themes in patient experience of surgical treatment for liver metastases. By so doing patient factors important to surgical decision making could be identified. The rationale behind this was that clinicians should better understand the patient experience and hence identify potential barriers to the treatment experience or avoid patient misunderstanding. As a phenomenological qualitative study which is now over a decade old, it was conducted retrospectively with 12 patients by means of a single semi-structured interview in patients' homes over a period of just over 12 months (July 2005 – August 2006).

Authors/ Year / Journal	**Place of study**	**Sample size & features**	**Treatment inclusion**	**Method**	**Main findings**
McCahill & Hamel-Bissell (2009) Palliative and Supportive Care	Vermont, USA	n=12 7 men 5 women Median age = 63	Surgical resection for CRLM liver metastases, ablation alone, ablation plus liver resection, laparotomy only (Mixed treatment sample)	Phenomenological qualitative approach. Retrospective Semi-structured interviews.	7 main themes having impact on treatment experience; 1) communication with health care provider 2) support from others 3) own attitude 4) cure uncertainty 5) coping strategies 6) hospital care concerns 7) internet information

Table 3.1: Key qualitative related patient experience, colorectal liver metastases resection

The participants had a mean age of 63, which is within the expected norm for those with bowel cancer. The age range of 43-75 years also reflects that these patients were not in senior decades where surgical fitness of additional co-morbidities generally makes it more difficult to proceed with surgical resection. Ten participants had colon cancer and two rectal cancer, with seven men and five women being interviewed. None of these patients reported any symptoms which again is typical with this patient group and typifies the reality of a well patient group with metastatic liver only colorectal disease. Patients initially were reported to have had liver only metastases and had undergone liver resection, ablation or both over a three and a half year period (January 2003 – June 2006). The lengthy retrospective period did mean that for some patients, an interview was being conducted 2 years after the treatment which could pose a long period to recall information. This was likely to reflect the small patient caseload in the early to mid first decade of 2000 and the often lengthy treatment period for some patients.

The study did acknowledge that including only patients who had a successful outcome from treatment for interview may bias results towards a positive experience. In order to avoid this, the researchers included three patients who developed further recurrence which was then not amenable to further surgery. This would be an important consideration in sample inclusion for any future study. However, on further examination of the surgical liver procedure only one of these patients had undergone a hepatic wedge resection. One patient had undergone radio frequency ablation (RFA) as discussed in chapter 2 and the other had undergone an exploratory laparotomy only. The laparotomy would not fall within the original suggested criteria for the study, i.e. liver resection, ablation or both and perhaps this patient should have been excluded from the study.

This presents one of the main difficulties with the study in that it does not include patients experiencing homogenous treatments. The patient sample included two patients who were treated with radiofrequency ablation (RFA) as their first treatment before liver resection and a further two who had RFA alone. Considering it is recognised that RFA is not as effective as surgical resection (Wong et al 2010), it is unclear as to the purpose of their inclusion as the rationale and explanation for treatment would be different from that of surgical resection. As discussed in chapter 2, RFA alone is often performed percutaneously in a radiology department and is therefore less likely to be seen primarily as a surgical treatment. It may be that the RFA reported in this study was performed in surgical conditions with a general

anaesthetic rather than percutaneous but it is not clear. This may simply reflect changes in practice as treatment develops.

Much of the focus of the study was on the expectation from the surgical consultation rather than across the pathway as a whole and sought to identify common themes in "order to identify factors of importance in treatment decision making" (McCahill & Hamel-Bissell 2009, p.65). Focusing on the surgical consultation, it can appear that the decision to proceed to surgery was to be carefully weighed up in terms of a treatment preference. The reality may be for those with metastatic disease that there is less of an option in making a decision as the realisation of what it means to decline treatment is evident. Certainly, all the patients viewed the surgery as holding no guarantees for disease cure but yet was seen, at the very least, as an opportunity to extend their lives. The authors acknowledge that they did not include any patients who were offered surgical treatment but declined. It is not clear if such participants were available during the recruitment time as declining treatment is itself an important and valid decision to support patients through. The participants saw the overall decision for liver surgery to involve several steps rather than being seen as one definite point or event. This is interesting as health care professionals can often pinpoint when a decision has been made to go ahead with surgery, but the patients in this study are experiencing a continuum of events which take them closer to the actual surgery and recovery phase. This continuum involves, initiating the idea to go ahead with a surgical option, undergoing surgery, recovery period and living with the consequences of surgery. These events are a continuum, wrapped up in the very context of waiting.

Using Colaizzi's procedural steps in the data analysis, McCahill & Hamel-Bissell (2009) revealed six main themes that had reflected on the patient experience; communication with their health care provider, support, personal attitude, care uncertainty, coping strategies and hospital care concerns. The communication style of their health care provider (surgeon, oncologist or nurses) helped to set the tone of their treatment experience. Examples of positive communication included, thorough explanations, honest appraisal of risks and appropriate non-verbal communication which helped to give patients trust and confidence. Negative communication styles were experienced when patients felt rushed or a treatment option appeared to be forced upon them rather than including the patient's opinion. In the same way it was recognised that support from others was key in undergoing treatment and positive and negative factors also applied. All patients noted that support from primarily

family and secondly social networks outside the health care environment, gave them hope and encouragement to continue with treatment. Outside support could also be negative at times when family members became overzealous to influence treatment decisions. External support networks while acknowledged by health professionals as being important in preventing isolation (Macmillan Cancer Support 2013) are largely invisible to the clinical teams. The daily impact of the process of an individual being considered for CRLM must have its strain on family members and it is essential that those caring for the individuals also have access to appropriate support.

With regard to the patient's own attitude, all patients noted that having a positive outlook and resolve to have liver surgery would help to contribute to a positive outcome. This did not mean that they were responsible for the outcome but that through this life changing diagnosis they were free to concentrate on the important things in life such as family and previously meaningful situations in life were now challenged. The tension of having treatment to extend their life but with no absolute certainty was noted in, arguably, the key theme of cure uncertainty. All patients were under no illusion that the cancer could return and as a result the concept of waiting returned as a feature in the recovery period and was especially heightened during waiting for results of follow-up scans. Coping strategies helped patients to adapt to the life changing diagnosis such as taking a day at a time, living in the moment and facing emotions rather than hiding them. In the theme hospital care concerns, negative concerns included lack of communication among inpatient staff which left a negative impression on their hospital stay where help received was noted to leave a positive impression. It was not clear whether this inpatient stay related to their surgical experience or also chemotherapy experience. Lastly internet information, was seen as more of a support for family members than for patients. Six patients noted the lack of information on surgical resection of liver metastases and what was there was very negative about the process which often led them to avoid the internet. Overall the study showed that patients showed a high level of satisfaction with treatment despite three of the group sustaining recurrence. McCahil & Hamel- Bissell (2009) conclude that further work, especially on a larger scale, was required to validate these findings.

3.3.2 Patient experience of liver transplantation for colorectal liver metastases

Considering that there are no further published qualitative studies on colorectal liver resection, the net needed to be cast further afield to capture associated surgical literature.

The following study characteristics can be viewed in Table 3.2 below. The Norwegian qualitative study by Vidnes et al (2013) reports the patient experience of surgical treatment of colorectal liver metastases using liver transplant. It is acknowledge this is not a commonly used approach.

Authors/ Year/ Journal	Place of study	Sample size & features	Treatment inclusion	Method	Main findings
Vidnes et al (2013) European Journal of Oncology Nursing	Oslo, Norway	n=9 6 men 3 women Median age =56	Liver transplant for CRLM metastases	Qualitative approach Retrospective Semi-structured interviews, 6 months after transplant Data analysed by Kvale & Brinkmann's (2009) five steps of meaning	
Andersen et al (2012) Scandinavian Journal of Caring Sciences *(part of above study with quantitative approach)			Liver transplant for CRLM metastases	Quantitative (prospective) approach using EORTC-C30 at baseline, 3, 6 and 12 months after transplant	

Table 3.2: Related patient experience for colorectal liver metastases (liver transplant)

Liver transplantation is the accepted treatment for chronic and acute liver diseases and its use as treatment for colorectal liver metastases has been limited due to 1 and 5 year survival rates of 61% and 18% respectively (Hoti & Adam 2008). It has been more successfully used in cholangiocarcinoma (Rea et al 2005) and hepatocellular carcinoma (Onaca et al 2007) and with improvements in reported quality of life in general liver transplanted patients (Adam & Hoti 2009). The availability of liver donors is very limited in the UK so the approach of liver transplantation alone makes this study interesting. The study was a mixed methods study, to evaluate the use of liver transplantation in cure or prolonging life with 25 patients with colorectal cancer and liver only metastases. The first study (Vidnes et al 2013) focused on 9 of the 25 patients to conduct semi-structured interviews at least 6 months following liver transplant. The second study reported by Andersen et al (2012) with the same patient group, used the validated EORTC quality of life questionnaires a year after treatment was complete to ascertain recovery and function following surgery. Interviews were conducted over a one and half year period between 2007-2008 with patients who had received liver transplant between November 2006 and March 2008. The patient group were slightly younger than those in McCahill & Hamel-Bissell's study (2009) with an age range of 50-63 and a median age of 56 years.

Three main themes emerged from the interview data; a renewed gift of life, living between hope and despair and back to normal life. These themes resonate with those identified in McCahill & Hamel-Bissell's study (2009) where patients were both grateful and realistic about the opportunity for liver resection to prolong their life, rather than necessarily provide a cure and seeking to find a new normal in life following surgery. Despite both studies using surgery to treat CRLM the Norwegian paper does not refer to the American study. All nine patients also reported equal or better global health scores compared to baseline scores and reported good functional scores during follow-up points at 3, 6 and 12 months following liver transplant (Andersen et al 2012) showing it to be effective in this initial year period. A further period of follow-up would be necessary to further evaluate the value of liver transplant in CRLM considering that with the use of cytotoxic medication alone, disease progression often exceeds 18 months (Choong & Ammori 2014). Both liver resection and the more experimental liver transplant represent aggressive surgical intervention in the management of liver metastases. Notably, although Andersen et al's study (2012) refers to the use of transplant, their quality of life (QoL) results echo previous liver resection studies showing overall good quality of life following liver resection using patient reported QoL measures

(Martin et al 2007, Wiering et al 2010, Rees et al 2012). Utilising aggressive surgery becomes more acceptable in the context of quality of life.

While it is not the remit of this chapter to discuss the use of quantitative QoL tools, it is important to note QoL tools are a significant in assessing patient related outcome and will be referred to more fully in Chapter 5 when considering relevant study methodology. Broadly speaking, the tools are a multidimensional construction with objective and subjective dimensions rated on a continuum of severity.

They are often used to provide a longitudinal view of patient recovery, symptoms and short-term impact of treatment. Such measures are useful in providing information on the suitability of different treatment approaches and can inform decision making. However, there is much debate on QoL tools, how QoL can be defined and measured. The EORTC QLQ-C30 and LMC questionnaires were primarily developed to measure short-term QoL and major on physical symptoms. In considering study design some thought was given to the use of these questionnaires for this study. However, this was ruled out and the reasons for doing so are detailed in Chapter 5, Methodology. It became necessary to understand the reasons for using these tools and whether they would add anything to understanding an experience that was not dominated by physical symptoms. I wanted to understand the patient experience of being considered for liver resection up to the point when a decision was made rather than focusing on how the disease and treatment would affect physical health during the period of consideration for CRLM resection. Another important aspect to consider is that the impact of physical changes and the psychological change during this process of being considered for liver resection may not necessarily be linked to the severity of the disease. It is not always the severity of the condition that is an indicator as to how someone manages but may be how an individual perceives and adjusts to their situation that determines overall impact, as identified by one study concerning depression, anxiety and pain (Brown et al 2010).

3.3.3 Patient experience of long-term survivorship from colorectal liver resection

The final qualitative study of interest is Whale's (2016) doctorate study in Health Psychology. The aim of the study was to investigate the impact of CRLM resection on patient longer term quality of life and survivorship experience. Whale was conscious of the limitations of quantitative quality of life measures in assessing longer term quality of life. Study characteristics can be viewed in Table 3.3 overleaf.

Fifteen patients were recruited from a previously recruited cohort of 241 patients who were recruited between April 2004 and May 2007 as a means of assessing longer term quality of life up to 5 years following standard resection of metastases from colorectal cancer from two UK sites in Bristol and Basingstoke.

Authors/ Year/ Journal	Place of study	Sample size & features	Treatment inclusion	Method	Main findings
Whale (2016) PhD thesis, Health Psychology University of the West of England, Bristol	Bristol & Basingstoke, England	n=15 for patient interviews 5 women 10 men Age range 66-85	Liver resection for CRLM resection	Qualitative study on back of quantitative quality of life study	<u>Qualitative</u> 3 main themes with 11 sub themes. 1) Cancer and me; establishing a relationship with cancer 2) Living with cancer 3) Aligning the long-term impacts; the person I've become

Table 3.3: Related qualitative literature within quality of life study, colorectal liver resection (Whale 2016)

Whale had been involved in some of the recruitment to the larger EORTC study at the University of Bristol (Rees et al 2014) which was a longitudinal prospective cohort investigating patient reported outcomes. Patients completed the EORTC QLQ-C30 and LCM questionnaires at four weeks prior to surgery, followed by 3, 6 and 12 months after surgery and a final long-term questionnaire at 5 years following resection. It was during Whale's involvement in quantitative quality of life data collection that she became curious as to whether the questions were capturing the full patient experience. Whale (2016) felt that she needed to understand the experiences of long-term cancer survivors and questioned if QoL would accurately provide a detailed picture of long term survivor experiences, particularly if there was uncertainty over how objective a measurement QoL could be and whether it was better designed for capturing short term physical change. QoL can change over time and it therefore seemed short-sighted that the same QoL measure and domains could be used at diagnosis, treatment and short-term recovery and still be appropriate when assessing longer-

term needs. Whale believed that survivorship and post-cancer identity would become a more pertinent focus for long-term cancer survivors.

In comparison, Whale (2016) opted for qualitative enquiry with the CRLM resection group believing that this would provide greater insight into a neglected area of investigation. Her aims were to explore the long-term quality of life and survivorship experiences in patients having had CRLM resection using qualitative interviews and in so doing to explore the relevance of EORTC QLQ-C30 and LMC questionnaires.

Whale's (2016) study revealed 3 themes which provided insight into the meaning of survivorship at least five years following CRLM; 1) 'Cancer and me; establishing a relationship with cancer', 2) 'Living with cancer' and 3) 'Aligning the long-term impacts; the person I've become'. Although participants did mention some on-going physical affects, the focus of the interviews centred on coming to terms with their cancer and how they had coped with their experiences and adapted to their new post-cancer self. Coping strategies were utilised which helped to foster a positive attitude such as reframing their focus in life and gaining positive outlooks from religious and spiritual beliefs. Living with cancer, acknowledging and adapting to the person they had become as a result of their cancer experience was necessarily an on-going experience.

Whale concluded that the EORTC QLQ-C30 and LMC measures did not address the issues of survivorship nor postcancer identity change, which is only apparent over time and not captured within the questions present on either questionnaire. With the use of qualitative interviews, Whale could see that individuals who experienced CRLM, used various coping strategies to deal with their experience. Some of these strategies were linked to changes in self and their identity as a result of the cancer diagnosis and treatment experience, or a new post-self. For others their experience was wrapped with a sense of meaning. This included a shift in priorities, renewed affirmation of life, greater importance on social relationships, increased empathy for others and changes in interpersonal relationships. Whale (2016) argued that the changes in identity and viewpoints as part of a new cancer self were a form of post-traumatic growth, as a result of undergoing a traumatic experience such as cancer (Zoellner & Maercker 2006). Post- traumatic growth is a direct contrast to the concept of post-traumatic stress disorder where an individual had no benefit from experienced trauma only pain and anxiety (Hadit 2006). The period that Whale (2016) refers to, was not a natural

process of personal development but could be better understood as the process of putting back together the pieces of self that were shattered as a result of the trauma and finding meaning from that experience (Thornton & Perez 2006). Experiencing a trauma can change the internal schema of an individual's world view, the way the see the world, self and others (Weisman & Worden 1977). This idea of a new lens from which to see the world after cancer is well supported in the literature and also was a sentiment picked up from McCahill & Hamel-Bisell's (2009) phenomenological study.

3.4 Colorectal liver metastases; a comparable experience

A number of qualitative studies directly related to the experience of undergoing colorectal primary surgery have used phenomenological method and, as such, may have some bearing on patients being considered for liver metastases surgery.

3.4.1 Perspectives from phenomenology accounts in colorectal primary surgery

Moene et al (2006) conducted interviews with 28 patients in order to study how they experienced their existential situation one week before colorectal surgery. Analysis was influenced by van Manen's four fundamental lifeworld themes (van Manen 1997). Van Manen sees research efforts into human science as explorations into the structures of the human lifeworld. He devised four fundamental lifeworld themes (or existentials) to guide the reflection and analysis of human experience. These themes are the existential of lived space (spatiality), lived body (corporeality), lived time (temporality) and lived relation (relationality). Half of the patients in the study sample included patients having surgery for benign colorectal disease, so it is perhaps no surprise that differences were found in how patients with benign disease viewed their existential situation. The two main differences were found in the areas of spatiality and temporality. Patients with benign disease experienced a sense of increased spatiality, primarily feeling that restrictions in life and social interactions would be lifted as a result of the surgery whereas patients with malignant disease felt that their world was becoming increasingly narrow, that life was going through a new phase and that this may mean the end of life was at hand. Similarly, patients with malignant disease, experienced temporality or the sense of time differently feeling especially anxious leading up to the surgery whereas those with benign disease were more able to use the time before surgery to gather energy, relax and prepare. With regard to experiencing corporeality, both those with benign and malignant disease, felt that they were entrusting

their bodies to be cared for and had confidence in the competence of the staff whom they had met. A further aim of Moene et al's (2006) study was to explore the value of the encounter between the preoperative nurse and patient and this was examined under van Manen's theme of experiencing relationality. Although Moene et al (2006) acknowledge that relatives played a vital support role, patients also valued the staff they met before the operation. Key aspects of these interactions were noted as providing security and continuity which were important in establishing a relationship. However, the role of the preoperative nurse did not feature in the interview statements and Moene et al (2006) concluded that nurses could do more to address existential concerns. This is particularly pertinent when considering that many of the concerns patients have in life limiting illness are by nature concerns that touch on the very meaning and value of life.

Perhaps it is too easy to overlook such concerns in the clinical 'doing' of practice whereas an individual's attention may be focused around how clinical aspects will impact upon their life. Often the individual focus may centre around existential questions on 'being' rather than the 'doing'. The study is of interest to the experience of those being considered for CRLM, as it confirms that those with malignant colorectal primary disease have apparent existential concerns which health care professionals may not be detecting or missing the opportunity to address. It may also be postulated that existential concerns may be heightened in patients with metastatic colorectal liver disease who are being considered for CRLM where knowledge that potential surgery may significantly increase life while concerns may grow about maintaining eligibility for surgery. At the time of writing, this study is over a decade old and while the contribution of the preoperative nurse is referenced, since then the input of specialist team nurses or nurse specialists have also been acknowledged in the management of cancer (Leary et al 2008, National Cancer Action Team 2010, Royal College of Nursing 2010, Department of Health 2011, Macmillan 2015, Henry 2015, and Vidall et al 2015). The fact that the role of the nurse was seen as invisible in Moene et al's study has application for nurse specialists who are well placed across the care trajectory in helping to manage a period of uncertainty for those being considered for CRLM. That is not to say, that existential concerns should not be addressed across the wider team, as indicated in this study by the peri-operative nurse when concerns about getting through the operation are especially foremost and surgical risk is considered.

Worster & Holmes have published two papers relating to the same study in 2008 and 2009 with 20 participants (10 male and 10 female) who underwent abdominal surgery for a colorectal cancer primary. Interestingly, the initial purpose of the study was to discuss the post discharge experience as the main focus of the study but the study took an unexpected turn when they discovered that the participants chose to talk about the their pre-operative experiences, relating much back to diagnosis and their emotions in preparation for surgery. Participants were approached and interviewed four weeks following hospital discharge and data were analysed using Giorgi's (1985) analytical method. Six key themes were identified as the following: I couldn't believe it, being alone, informational needs, protecting family, unexpected consequences of investigations and loss of control. The key themes they felt could be a common feature of any cancer type and not necessarily colorectal cancer but had particular bearing on the need to address such issues in the workup to surgery. The fact that there was a desire to return to reflect on how things began which had led them to the need for surgery suggested the beneficial or therapeutic aspect of these interviews, something of which a few participants had openly commented to the research interviewer at the time of the interview. The role of the Clinical Nurse Specialist was acknowledged during these interviews in helping to manage some of the concerns raised from the themes and to navigate the way to surgery. A key message of the study was the need for patients to be the guide of the level of information they required in order to help gain a sense of control over an uncertain process and time in their lives.

Worster & Holmes continued to write up their intended study when they published the post-op experiences of the same group of patients in 2009. Again, using Giorgi's (1985) data analysis method, eight themes emerged. These were listed as the following; 'thank goodness that is over', 'needing information', 'loss of dignity', 'personal appearance', 'loss of control and mobility', 'inability to eat and drink', 'lack of sleep' and 'discharge'. These themes are not surprisingly linked to physical aspects of recovery as would be expected for four weeks after surgery. There is however, no mention of whether any surgery was conducted laparoscopically as this may have had a bearing on that initial recovery or patient's perception of adjustment in that immediate post-operative period. It did however acknowledge that the impact of Enhanced Recovery After Surgery (ERAS) may have a bearing on recovery in the future. Here it can be seen that the context of recovery and advances in nutrition, exercise and surgical technique can all feed into the patient's post-operative recovery experience.

A further phenomenological study by Khatri et al (2012) reported on the experience of twelve patients in Sydney, Australia three to six months after undergoing gastrointestinal surgery of curative intent. In addition to eight patients with colorectal cancer, it also included oesophageal and pancreatic patients and reported on the experience of six carers, known to participants. The study was robustly conducted with all three nurse consultants who conducted patient interviews having undergone interview training and research based interview methodology. As such the study is well presented and is rich in data. All interviews were conducted via telephone due to the practical constraints in covering a wide rural area. The lack of face to face contact, did not seem to hinder the depth of data but there can be constraints to not being directly present with the interviewee such as not being able to consider non-verbal communication which is a rich source of context for the whole of the interview process (Kings & Horrocks 2010).

Overall the findings showed that these patients encountered a sense of altered time and temporality which was in line with the Heideggarian philosophy used to underpin the study. Four key themes summed up the aspect of the temporal experience of undergoing gastrointestinal surgery, 'a recall of intricate details', 'waiting', 'a changing pace of time' and 'being towards death'. Despite being interviewed three to six months following surgery, the first theme, a recall of intricate details is a striking finding.

3.4.2 Relevance of findings

In clinical experience, patients often recall and relay intricate details during history taking. Often these details are conveyed in a setting where time is limited perhaps during a clinic consultation, and often the history taker is keen to get beyond these details to what is of clinical significance to them. In such cases the recall of intricate details is often something to be skimmed over and are often lost and superseded by more relevant details as the history taker sieves for information. What is important from Khatri et al's (2012) study is that it gives an understanding of why patients search to recall specific details of their lives. Firstly, it provides a context as to what was going on in their lives and hence what was important to them at the time. Secondly, when faced with the temporality of life, an awareness of time and the need to pin events to a date often become important. This echoes Heideggar's view of time in that we can only understand the phenomenon of time in relation to death, an event which is outside of our life but yet marks the end of life (Alweiss 2002).

The second theme of 'waiting' was a dominant experience in this patient group. The relevance of waiting is borne out of uncertainty as to what lies ahead following surgery, perhaps by way of complications and as Khatri et al (2012) suggest this waiting is exacerbated by a patient's awareness of mortality when faced with cancer surgery. Indeed, cancer treatment may be seen as a continuous cycle of waiting and is influenced by a perception of cancer as a growing entity that remains a threat until it removed. During this wait, Khatri et al (2012) found that it is natural for there to be a heightened anticipation of outcomes at various stages along the way and that this is relieved only by appointments. Irritability is a common feature and reports from carers and participants suggest it is to be expected. A health professional who is able to help prepare and manage expectation throughout the different stages of treatment pathway may help to level out some of this anxiety through the process of waiting.

The third theme, 'a changing pace of time' was also identified. Participants in Khatri et al's (2012) study spoke about a slowing down of certain aspects of life and a speeding up of other areas. To many it was as if there was a holding pattern forced on life. The final theme of 'being towards death', conveyed that despite all surgery was of curative intent, yet life was very much threatened. This feeling followed afterwards when results were given and despite being given good news, patients felt it was hard to let go of the awareness of mortality and difficult to have a longer-term perspective on life.

While the study acknowledges the limitation of different types of gastrointestinal cancer and admits that the purpose was not to make a direct comparison, the findings combined with the Moene et al's (2006) and Worster & Holmes (2008) (2009) studies, have relevance for the subset of patients being considered for CRLM.

3.5 Consideration of colorectal liver metastases resection; a parallel patient experience?

In the absence of additional experiential research among patients with potentially resectable liver metastases, it is necessary to consider other literature related to the treatment of life limiting conditions where the possibility of further surgery can cure, extend life or control quality of life if the illness were not treated. One obvious area to turn to is the resection of other solitary lesions in colorectal cancer such as lung metastases or that of potentially curative peritoneal disease resection. However, while surgery in both these areas is increasing, as outlined in chapter 2, no qualitative studies have yet been published. Neither

have there been qualitative studies undertaken with those who have had liver resection due to secondary disease in other tumour groups such as breast cancer where liver resection is occasionally used. This makes drawing parallels with phenomenological studies in the use of liver resection in other primary cancers unfeasible.

With such a sparse literature base to work from, a wider literature net requires to be cast in life limiting conditions where similarities in the pathway to surgery or nature of disease may exist. From the primary qualitative research study by McCahill & Hamel-Bissell (2009) there were both external factors and individual factors which helpfully contributed to the patient experience of the pathway to CRLM resection. To summarise from the previous section, external factors were those of the communication style of health care professionals, external support, the uncertain nature of the pathway itself and experience during hospital stay. Those individual factors noted were personal attitude and coping strategies. One area where there may be similar themes identified is within the speciality of liver transplantation. It could be argued that the process of 'being considered' for CRLM resection and for a liver transplant is a similar concept in the face of a life threatening illness and this will be explored in this section.

3.5.1 Liver transplant

A liver transplant involves the surgical transplant and acceptance of a liver from a deceased donor. A strong, qualitative research base has developed in liver transplant mainly from the mid 1990s, since it gained acceptance as a successful and optimal treatment for end stage liver disease with 1 year and 5 year survival rates of 87% and 73% respectively (Adam et al 2012, Alqahtani 2012). The widespread adoption of cyclosporine based immunosuppression as routine post-operative procedure and the standardisation of the transplant procedure during the late 1980s greatly contributed to now survival picture (Adam et al 2012). ESLD(End stage liver disease) results from advanced liver damage, more commonly seen through hepatitis C, alcoholism and cholestatic liver disease, such as primary biliary cirrhosis (Bjørk & Nåden 2006). Cirrhosis of the liver is a common feature where normal liver architecture is converted into abnormal nodules which contributes to portal hypertension and other complications such as gastrointestinal bleeding (Brown et al 2006). The primary reason for liver transplant of ESLD include commonly experienced symptoms of fatigue, muscle weakness, itching, nausea, weight loss, jaundice and fluid retention (Wainwright 1997, Brown et al 2006, Findlay et al 2011). Encephalopathy can also occur with memory loss,

confusion and eventual coma (Findlay et al 2011). Like CRLM resection, the possibility of liver transplant has arisen as a consequence of innovation in surgical technique, however the scarcity of organ donation limits its availability to those in need. In view of the shortage of cadaveric livers, attempts have been made at prioritising patient need based on statistical formulas that predict who is most likely to die. The Model for End-Stage Liver Disease (MELD) is a commonly used scale with a higher score representing a higher priority for transplantation (Brown et al 2006). Introducing such methods have not been without their difficulties and patients themselves have often reported being at the mercy of the MELD. Larson & Curtis's (2006) perspectives on an ESLD case study, with the sub-title of 'Too Well for Transplant, Too Sick for Life' aptly captures this feeling, with patients themselves feeling symptomatically in need of a transplant but their MELD score suggesting otherwise.

Due to the shortage of cadaveric livers, living-donor liver transplantation (LDLT) has been developed to address the shortfall, with the first adult transplant taking place in 1994 (Hashikura et al 1994). However, living-donor liver transplant is also not without risk for the donor (Watanabe & Inoue 2009).

3.5.2 Liver transplant: a comparable goal?

The goals of liver transplantation are not dissimilar to the goals of liver resection; firstly to prolong survival and secondly to improve overall quality of life for patients (Alqahtani 2012). The only point to note is that during the wait for liver transplant, patients' quality of life is generally affected to the degree where life is restricted in a physical means, whereas patients who are being considered for liver resection are usually asymptomatic as the intention is to use liver resection at an early phase of liver metastases development. This is a marked difference between the potential liver resection group and liver transplant and may have considerable impact on the emotional and physical state of the individual. Should the CRLM disease remain, only then would quality of life issues would become a feature. In both liver resection and liver transplant, surgery should be considered for appropriately selected patients for whom it would extend life expectancy beyond the prediction of the natural history of their disease. In both ESLD and CRLM without surgical treatment, there is no hope of cure and death is inevitable. Therefore, it is reasonable to consider qualitative transplant literature for this reason. In addition, both disease processes involve multidisciplinary input, with the transplant team having a well established nursing role in patient counselling and support (Levenson & Olbrisch 1987, Brown et al 2006).

Liver transplant has a richer base in qualitative studies stemming from the late 80s. One early study by Levenson & Olbrisch (1987) studies the relationship of the transplant team with patients during the wait. Interestingly, patients found that silences during the wait often felt like an avoidance of contact by the team and made the wait more difficult. This does raise the question of the importance of confronting such silences during difficult waiting periods of treatment by means of regular contact.

Much of the early focus on qualitative studies has been on aspects of pre and post treatment often involving quantitative quality of life measures as the physical change in health took place. Wainwright (1995) used grounded theory method to analyse data from in depth interviews covering patients adjustment post liver resection. His findings from the patient's perspective viewed liver transplant as one of transformation, covering a five stage trajectory of 'receiving the transplant', 'improving in hospital', 'improving at home', 'feeling well again' and 'reciprocating'. Jones & Egan (2000) also looked at the patient experience of life pre-transplant, during and after transplant and identified themes of quality of life, and factors of concern relating to finance, social support and psychological coping. One aspect which is apparent although not always labelled as such in the qualitative studies is the feature of waiting. This is common, both to the colorectal liver metastases resection pathway and the pathway to liver transplant in end stage liver disease. In Brown's et al study (2006), eight themes emerged which were seen as important elements of the wait for liver transplant (see Table 3.4 along with the themes from the Norwegian study by Bjørk & Nåden (2008).

Waiting themes identified in consideration of liver transplant for ESLD	
Brown et al (2006), USA	Bjørk & Nåden (2009)**,** Norway
1) Transformation of self	1) Uncertainty
2) Doctors, teams and trust	2) Mental wear and tear due to reduced energy
3) Elation to despair	3) Existential brooding about the meaning of life
4) Loss	4) Feelings of being mentally strong
5) Questioning the process	
6) Searching	
7) Coping	
8) Paradox of Time	

Table 3.4: Main qualitative studies investigating waiting in liver transplant for ESLD

3.6 An identifiable feature of waiting

There are two studies where the feature of waiting has been purposely investigated in liver transplant, an American study by Brown et al (2006) and a Norwegian study by Bjørk & Nåden (2008). Brown et al's (2006) study is clear in its intention to investigate wait, which the authors state arose from a feeling of being "ill at ease" (p.119) with the status quo of the ESLD process. As psychiatrists they were involved to assess and verify that patients waiting for transplant, due to alcoholic and drug causality, had been abstinent for six months. Observationally in practice, Brown and colleagues could see a repetitive feature of strain on patients in the process of waiting. They write,

> *"Out of the silences and repetitions of their time on the waiting list, an occasional voice was heard. It was at times an articulate plea for recognition of the uniqueness of their experience." (Brown et al 2006 p.132)*

This prompted one of the authors to "wonder about much more that was left unsaid and unexplored" p.132). Certainly, this feeling is echoed in the reason for the study detailed in this thesis. The impetus for study was through having a feeling of being ill at ease that the process of being considered was having a significant effect on those patients waiting for surgical resection. While it has been exciting to see the developments in the management of metastatic colorectal cancer, observationally, it can be seen that pathways of treatment have become more complex than the traditional elements of surgery plus or minus chemotherapy used in the palliative management of CRLM. In addition, the reality is, that the nature of such complex treatment pathways are often managed by different teams within their own discipline and departments, albeit acting as one commonly named team with shared decision making taking place through the multidisciplinary team meetings. An added element for consideration is that the teams sharing responsibility are often located on different hospital site locations which may prove more difficult both for patients and professionals in terms of pragmatics of management and communication. It is not unreasonable to suggest that as treatment pathways become more complex, a more complex care experience is created? In such situations, patients can move 'out of view' of their central team who have referred on for expert input. If communication and support is not culturally similar across different hospital sites, this may create a feeling of invisibility for the patient. Perhaps, by the very nature of surgical developments for metastatic CRLM, health professionals inadvertently invite patients to consider treatment where nothing of the

impact of that treatment is really as yet known. Indeed, Brown et al (2006) stated that the concern to investigate the liver transplant experience was "initiated by a sense of complicity in their suffering". The question then arises as to whether health professionals, have imposed a system upon patients that increases the burden of waiting? As Brown et al (2006) write,

> *"What happens in the waiting process might contribute to the comorbidity of illness and poorer quality of life" (Brown et al 2006 p.120).*

If this is the case, then how we navigate patients through that wait is of consequence, particularly if it has an impact on their health. Three key concepts of waiting from the domains of patient experience literature in CRLM, colorectal primary surgery and liver transplant that are worth picking up on are isolation, uncertainty and survivorship.

3.6.1 Isolation

The Cambridge dictionary describes the noun 'isolation' as both

> *"the condition of being alone, especially when this makes you feel unhappy" and "the fact that something is separate and not connected to other things" (The Cambridge Dictionary, online, 2018).*

This definition is thought provoking in the area of CRLM as indeed with reference to any cancer type, there will be some patients who have access to good family and social networks to draw support from and others who have little in the way of social interaction. What is interesting is that perhaps this definition does not touch on the idea that people can still be surrounded by others but have the feeling of being isolated. Indeed, perhaps being with others may even exacerbate feelings of isolation, with patients feeling separated from a commonality with those close to them even though they value their support. Macmillan published a report, (Macmillan Cancer Support 2013) revealing the difficulties that social isolation can have on people facing cancer treatment, although this mainly focuses on those who have little support. Macmillan's often heard line of 'no one should face cancer alone', rightly acknowledges that support from others is an essential part of helping to cope with a cancer diagnosis, yet patients can have good support but the feeling of being separate and not connected to other things, as the second noun definition by the Cambridge dictionary, has been a recognised feature of the literature reviewed which encompasses waiting.

This feeling of being alone, is also encountered at diagnosis. A qualitative study by Taylor (2001) using phenomenological methodology in 8 patients, only 4 weeks after diagnosis with a colorectal primary, discovered a striking and poignant theme of patients 'feeling on their own'. It is likely that none of these patients were metastatic from the outset as Taylor speaks about them going on to have primary treatment. In interviewing these patients, she found that there was a tremendous sense of wanting to protect others from what they were going through. Some of this may have stemmed from embarrassment that was specifically related to the nature of bowel disease but meant that close family and friends were often kept away from patients' true feelings. The researcher reports that an interesting benefit of this study was that some patients used the transcript which they were given from the interview and showed it to their relevant others as a means of expressing how they felt. What is not clear from the study was how other relevant others felt on reading the transcript or if there was any additional support offered to them. No doubt for some this may have been a useful exercise to encourage discussion but for others this may have a more negative impact warranting additional support.

With an increasing group of metastatic patients living with and concurrently undergoing multimodal therapy as part of ongoing treatment, there are likely to be issues of isolation to be addressed. This will potentially have an impact on family and social relationships, working patterns and finance related decisions. This may also be the case for those having treatment for metastatic colorectal cancer.

3.6.2 Uncertainty

Uncertainty related to cancer treatment is a major theme in the literature. Uncertainty is something from which we cannot escape in life. It is something which we are familiar with on a daily basis where we cannot predict what the day will hold and yet also at the same time uncertainty may be predicted at different stages of the life cycle, e.g. finding a job after a period of study or loss of job or readjusting to life after a bereavement. The concept of living with uncertainty is well documented in health literature, particularly where health concerns have a significant impact on life. A century ago, infections such as tuberculosis, influenza and pneumonia posed a serious threat to the health of the nation. The presence of death by way of infection, was commonly part of everyday life and for many cast an uncertain shadow over living. The last century has, however, seen major advances in science and technology which have led to phenomenal breakthroughs in infection control so that while as a society we have

largely fought infection, that effort has now turned to fight diseases such as heart disease and cancer. McKie writes,

> *'Cancer, so feared today, was not a pressing concern a century ago'*
> *(McKie 2015, para.2).*

Indeed, quoting John Williams, then Head of Science Strategy Evaluation and Impact of the Wellcome Trust, McKie goes on to say,

> *"If you don't die of an infectious disease, you will still die of something else. It's one of the certainties in life. So those who survived tuberculosis and flu eventually succumbed to something else – and very often that was cancer or cardiovascular disease, including stroke and heart attack*."
> (*Williams in McKie 2015, para.8).*

Death, as John Williams states, is one of the certainties of life. It is a risk with a certain outcome. The commonly quoted idiom, "Nothing is certain but death and taxes" which appeared in an identifiable format in a letter to Jean-Baptiste Leroy from Benjamin Franklin in 1789, (Pirie 2019) is a commonly understood phrase. It resonates to those understanding the transience of life. When considering the area of CRLM resection, the transience and fragility of life is starkly put into focus and is set against risk. The risk of not getting through to surgical resection makes mortality certain. At the same time, the operation is not without risk itself. It is important to ascertain if there are other areas where such uncertainty could exist in light of a similar risk.

Simpson & Whyte's (2005) qualitative study of 8 patients having completed treatment for bowel cancer found that all eight respondents highlighted the feeling of uncertainty over cancer recurrence. One respondent reported, 'It came once, it can come again'. This builds upon previous work in this area among patients having had potentially curative surgery (Galloway & Graydon 1996, Knowles et al 1999), although it could be argued that in the hepatic resection pathway, there is yet another level of uncertainty as for some patients they are waiting to see if their liver can be rendered operable by downstaging treatment.

Doyle (2008), in her literature review using Rodgers evolutionary method (Rodgers 2000) to identify key themes, found that uncertainty and living with cancer were inextricably linked. Even those with a good prognosis were reported to suffer from anxiety over the concern of cancer recurrence and could feel powerless as to how they could ease themselves from the oppressive anxiety itself. Interestingly, a longitudinal study by Mullens et al (2004) over 14

years, with 81 cancer survivors, found that those who had low level risk perceptions of a colorectal cancer recurrence were more likely (not statistically) to adopt protective health behaviours to improve their lifestyle and well-being. It is difficult to know if modifying behaviour is a pattern that is associated within the context of metastatic disease. Certainly, as the number of cancer survivors living with metastatic disease increase, there may be lifestyle changes made to improve their general health. This fits in with issues of both self-management and survivorship.

While uncertainty can exist around the ontological questions of being, it can also exist around immediate informational needs. Beaver et al's (2010) well designed, exploratory study of the follow-up needs of 27 colorectal cancer patients, found that informational needs on completion of treatment were often unmet, as were psychosocial needs of dealing with cancer treatment. In fact those who had convential follow-up, were less happy with how their needs had been met than those attending a nurse-led model of follow-up. Kidd (2011), in critiquing this study, suggests that the results might have given reference to how demographic and disease specific issues may have shaped patients perceived needs at the time. Indeed, when looking at the postoperative experiences of twenty colorectal cancer patients, Worster & Holmes (2009) found that many of the patients' information concerns focused around physical needs due to the recency of their surgery. These needs might be very different at other points in their cancer journey. When considering those patients on the pathway to liver resection, issues pertaining to uncertainty and informational need might be very different yet again. Hansen et al's (2012) literature synthesis of patient uncertainty included literature related to oncology patients and suggested that interventions such as organising hospital trajectory, providing support through relationships and providing accurate communication could all be beneficial to manage uncertainty. Such measures could help patients live in the everyday while not letting distant treatment goals engulf living. Interestingly, from Brown et al's (2006) experiential accounts of liver transplant, the patients awaiting transplant often felt the goal of the liver transplant became the overwhelming focus, whereas living in the present ought to have been the tangible thing to focus on. As one liver transplant patient, poignantly expresses,

> *"The future is always the goal and the present is held up and forgotten"*
> *(Brown et al 2006, p.134).*

3.6.3 Survivorship

The previous two themes identified sit closely related to survivorship. Doyle (2008) writes that there is much emerging in this field but work is now long overdue due to an increase in cancer survivors. In seeking to define a cancer survivor, Doyle poses an interesting question, 'When does someone become a cancer survivor?' Is cancer survivorship purely related to prognosis? Interestingly, in metastatic colorectal cancer with liver metastases, a survival rate following hepatic resection can be as high as 50%. Van Cutsem et al (2010) point out that this is a recurrence risk comparable to having adjuvant treatment following bowel surgery. When this is taken into account we begin to see cancer survivorship in different terms, akin to that of a chronic illness which requires ongoing management (Aziz & Rowland 2003, The Scottish Government 2008). This has significant impact on issues of recovery and follow-up.

3.6 Chapter summary

This chapter has set out the main phenomenological studies directly relating to the qualitative experience of being considered for colorectal liver metastases resection. It began by looking at three main studies (McCahill & Hamel Bissell 2009, Vidnes et al 2013 and Whale 2016) which were directly related to the use of surgery in colorectal liver metastases. In the absence of further directly comparable literature, the literature search was widened to look at other phenomenological studies also concerned with surgery for a colorectal primary. It then drew upon phenomenological accounts of waiting for a liver transplant as a surprising comparable experience. The concept of a liver transplant has a generally accepted understanding as a significant ordeal, which if the goal of liver transplant is not met, means a significantly shorter life. When the emotional impact of CRLM is considered as comparable to a liver transplant, the psychological impact of being considered for a liver resection is not to be underestimated. Both processes consist of the certainty of the feature of waiting and for both the process could often be viewed as an active wait, with periods of treatment and follow-up to assess treatment. From the literature identified in this chapter, three aspects of waiting were selected as having particular bearing upon being considered for CRLM resection. These were identified as isolation, uncertainty and survivorship. It was these aspects of waiting when viewed in the context of the treatment development of CRLM that has led me to the concept of hope, a concept that holds the process of waiting together with evident uncertainty. For this reason, the concept and value of hope will be discussed in the following chapter.

Chapter 4

A dissection of hope in cancer; origin, form and function

"Hope is the thing with feathers,

That perches in the soul

And sings the tune without the words

And never stops at all"

(Emily Dickinson 1891, in Dickinson 2016, p.94.)

4.1 Chapter overview

The media have been quick to communicate treatment advances in cancer to the general public in what seems like an explosion of media coverage in the past decade, in particular. News broadcasting, newspapers, magazines and social media are quick to pick up on success stories of cancer treatment or the potential breakthrough of a new treatment and what implications that might have for individuals with a particular cancer. Charities too have ridden on the crest of success, and strap lines such as 'We will beat cancer sooner' as used by a well known cancer charity, suggest an urgency to finally eradicate this disease and the pain it causes to those in society. Looking back to the picture of cancer as evidenced in the 1950s and the huge advances made since, for example, in acute lymphoblastic childhood leukaemia (Pui & Evans (2013) it is understandable how we have cause to hope. There appears to be a growing global sense of hope in the progress evidenced in the overall trend of survival rates for example as seen in breast, bowel and prostate cancers. In many cases we can see that this gives rise to an individual sense of increasing hope in treatment when presented with a cancer diagnosis. As health professionals, we commonly hear individuals and their families speak of a time when an older relative had cancer and very little could be done, often to finish the conversation with the phrase 'that was then and this is now', expressing the idea 'that things [treatment] will have moved on'. Yet, we know that for many, the reality of living with cancer and a lack of treatment options are very real. Although there has been recognisable progress, the tangibility of hope is more nuanced when we get down to the individual level than we could be led to believe by media coverage alone.

The literature reviewed in chapter three has led to a necessary pause and reflection on the concept of hope together with the role which hope plays for individuals with cancer and how

this might have a bearing on those patients being considered for CRLM resection. This chapter will provide an analysis on the concept of hope before looking at the role of hope in those with cancer. It will include a reflection on the origins of hope, tracing it back to how it has been viewed in history with often an unfavourable stance before looking at two key theories of hope, Snyder (2000) and Herth (1990). It will conclude with the implications of hope in nursing and how hope may be fostered in situations where uncertainty is high, which may have bearing on those being considered for liver resection. It is the philosophical interrogation of hope that aids understanding and interpretation of the data and in turn, lends a practicality to how health professionals might utilise hope amidst uncertainty.

4.2 The meaning and origins of hope

Hope is a multifaceted, abstract concept and while it may differ in relation to an individual's circumstance it is also a concept which is individually realised by its presence or its absence. Nweze et al (2013, px) in their analysis of the concept of hope, suggest that hope is appealing to us because of the focus it gives "to the various ways in which human beings survive in life, despite the many traumatic events that lead to the disruptions of life that occur". Few of us could fail to identify with either the traumatic life events or the ensuing disruption encountered as a result and so it is of little surprise that the entity of hope is something which has captured the fascination and speculation of theologians, philosophers, playwrights and songwriters across many centuries, in a bid to understand why we continue to hope when events happen that are not in our plan or sphere of control. Indeed, Hans-Georg Gadamer wrote with this sentiment very much in consideration in his major philosophical work *Truth and Method'* (1960), that of interpreting events in life, even though we may not be consciously interpreting as a response to those events. In the prelude to the second edition, he writes,

> *"My real concern was and is philosophic: not what we do or what we ought to do, but what happens to us over and above our wanting and doing". (Gadamer 2013, p.xxvi)*

With such general appeal and potential value, there is also little surprise to find that the application of hope has also been discussed extensively across different disciplines in literature (Cutcliffe & Herth 2012). The recognition of the importance of hope to nursing practice has grown since the early 1990s with the contribution of Herth's work in how hope is fostered in the terminally ill (Herth 1990) and there is now an understanding that hope is

a basic value in nursing, being firmly rooted within nursing philosophy (Hammer et al 2009). However, it is noted that different interpretations and conceptions of hope exist within different disciplines (Hammer et al 2009, Nweze et al 2013) and for this reason, defining it with some certainty has proved difficult.

The word hope can be used against a continuum of situations with varying intensity of emotion, from the more mundane to the more poignant and serious situations in life. As both a noun and a verb it is a strong, active word and provides flexibility in the English language, ready to be applied with varying situation and sentiment. As a noun hope is defined as "a feeling of expectation and a desire for a particular thing to happen" and as a verb, "want[ing] something to happen or be the case", (Oxford University Press, 2018 para.1). The converse of hope is to be hopeless. Cutliffe & Herth (2002) acknowledge that the words 'despair' and 'desperation' also stem from the same Latin root as hopeless, which suggests a position on the further end of the spectrum of being without hope. A second, although less typical definition of hope is "a feeling of trust", (Oxford University Press, 2018, para.2) whereby the inference lies in trust in a relationship. This definition is not often alluded to in the hope literature but the relevance is worth noting in support of the idea that trust frequently goes hand in hand with an expectation that a relational being or a belief in a higher power can bring about change in a situation.

As a phenomenon, hope presents some unique challenges for theories of mind and theories of value. It is an attitude with a cognitive component, i.e. the idea that it is responsive to facts about how likely future events will happen but it also has a conative component, i.e., it reflects and draws upon our desires of what we want to occur. The interesting conundrum is that not all that we desire to happen is necessarily the result of a correct interpretation of events which raises the question could hope be reduced to the sum of our beliefs? The concept of optimism has often been taken as synonymous with hope yet hope can be used to desire an outcome which is very unlikely and does not expect to happen, such as the cure of a terminal illness. Optimism does not seem to have a place such a situation as the probability makes the optimism obsolete. The role of optimism will be discussed later in this chapter within the section on hope theory. Many philosophers feel that to understand hope properly is to see it as independent of an assessment of probability (Bloeser & Stahl 2017). This also raises the question that if hope still occurs despite evaluating the facts of probability which might render it useless, can it be misleading, distorting and unhelpful?

We can see that hope can be used within a continuum of situations from the mundane to the poignant and differs widely according to personal experience. Francis Bacon is reported to have said that 'hope is a good breakfast but it is a bad supper' (Bacon cited in Spedding et al 1859, p.168) while the following quotation from Benjamin Franklin hints at the futility of hoping alone without purpose,

'He that lives upon hope will die fasting' (Franklin 1848 p.2)

These thoughts prompt the question, is hope useful or is it merely an illusion? This also has bearing on how useful hope is when faced with extreme situations of health such as metastatic liver disease as discussed in this thesis. At this point it is worth pausing to look at different concepts of hope through history in order to give some context to these questions. By examining the origins of hope, we can see how historic thinking has helped to shape our current understanding of some important elements of hope, which are relevant to difficult periods of life such as life threatening illness.

4.2.1 Hope as viewed in ancient times

Early accounts of hope in Greek mythology, have often had negative connotations as something to be wary off which could mislead actions. An account by Thucydides suggests that those who hope seem to have a poor understanding of their situation and fail to come up with their own plans for success (Schlosser 2012). This account was often directly seen in the context of war, The Peloponnesian War in this case. In Hesiod's tale of Pandora after all of life's miseries had escaped from Pandora's jar, hope was the one thing that remained (Verdenius 1985), although there are differing interpretations of this. The more commonly understood interpretation is that hope was left in the box as a distinctly positive force for comfort amidst widespread evil. While Verdenius suggests that it may have been left in the box to keep hope away from man as hope has an undesirable consequence often resulting in lack of productivity through idleness (Bloeser & Stahl 2017). The use of Pandora's box is a good example of how the concept of hope is different to each of us and how cultural interpretation plays a bearing on individual meaning. Plato too reports hope as a negative influence in *Timaeus* when he recounts that divine beings have given a number of attributes along with a 'gullible hope' (Plato, *Timaeus* as translated Waterfield, 2008 p.69b). However, in the Philebus he gives a more favourable view of hope suggesting that expectation of future pleasures are called hopes (Forte 2016).

Likewise, Aristotle recounts a more positive view of hope when he discusses the virtue of courage (Bloeser & Stahl 2017). In his discussion it would seem there is a contrast between hope and courage yet there is also a link between hope and courage by exercising an inner confidence. Aristotle speaking on confidence writes,

> *"The coward, then, is a despairing sort of person; for he fears everything. The brave man, on the other hand, has the opposite disposition; for confidence is the mark of a hopeful disposition". (Aristotle, The Nicomachean Ethics, 2009 p.51).*

This is interesting because not every hopeful person could be viewed or may necessarily see themselves as courageous but Aristotle by virtue sees every courageous person to be hopeful. In this way the action of being hopeful creates confidence. Although not discussed, perhaps the confidence that others exert in a situation may affect the individual's action of hoping. This in turn may lead to a position of trust which may also help individual's hope in others to see them through a difficult situation, despite the overall outcome.

In ancient Greece, the concept of hope was less well viewed by Stoic philosophers. Perhaps this was not surprising, as the practice of Stoicism was developed by Zeno Citium around 3rd century B.C (Bloeser & Stahl 2017) and focused on development self-control and fortitude as a way of overcoming emotions which could be seen as destructive or unhelpful. Its basis has an important inference on hope as its intention is to transform emotions rather than deny their existence altogether through the practice of asceticism, that is, abstaining from pleasures of the world. This in turn should create clear judgement and ultimately the goal of freedom from suffering. It can be seen how by 'turning off' the mechanism of hope that this may lead to unnecessary suffering if the mind is not allowed to follow in a meaningless or futile hope. Seneca, in particular, revealed a negative view of hope through Stoic philosophy in that he believed hope to be caught up with fear. He said,

> *"Widely different though they are, the two of them march in unison like a prisoner and the escort he is handcuffed to. Fear keeps pace with hope" (Seneca, 1969 as cited in Rorty 2003).*

Seneca, almost simplistically, felt that if we avoided hope we could avoid fear and this would lead us to concentrate on the present and thus achieve a state of inner calm with our current situation and environment. In this way, hope had little purpose in contributing to the view of

one's future. This is in direct contrast to the theological hope as outlined in the following section.

4.2.2 A Christian view of hope

The Christian view of hope has been focused on. This is not to say that in other major religions, hope is not evident but Christianity provides such a rich literary source of hope and has been the context of our cultural heritage in the UK. In addition, Christianity has either underpinned many of the major Western philosophers theories or has been referred to in order to reject Christianity as an alternative way of thinking. Theologically, the Christian perspective is wrapped up in hope. Cutcliffe & Herth (2002) state that,

> *"If hope is considered in terms of the Christian faith then it can be argued that hope has existed almost as long as man has existed."*
> *(p.833)*

The Christian faith is one of reconciliation between man and God, a rescue story and therefore one of hope. Hope is mentioned 129 times in the Bible and is connected with not just the present life but the securing of life after death which was made possible through the death and then resurrection of Jesus. In this way faith and hope are intrinsically linked and as portrayed by the theological philosopher, William Lynch (1965) seeing hope as a product of faith (Capps 2016). An example of this is seen in the book of Hebrews, Chapter 11, verse 1, "Now faith is confidence in what we hope for and assurance about what we do not see", revealing that hope appears to be a product of faith (Hebrews 11:1, NIV, 2018). This faith is expectant and confident and suggests something more than a short-lived hope but rather a certainty. Hope in this perspective is not restricted to life on earth but goes beyond death and provides meaning to that death and future existence beyond death.

Augustine and Aquinas see hope as one of the central virtues of a Christian belief (Bloeser & Stahl 2017). They do not see that the hope has formed the belief as if by some way of comfort but that the hope has is attributed to a rational faith and will therefore drive actions. In Romans 8, Paul states that believers have a certain hope and alludes to the idea that hope can often be the product of suffering, (Romans 8, NIV 2018). At this point, Paul is referring to the suffering that Christ went through but individually we can see that hope really comes into play in situations where individuals are struggling or suffering. Augustine distinguished hope from faith in that hope is therefore forward looking, anticipating a time when suffering will

be alleviated in a situation or ultimately will end in death which will herald the afterlife. Faith is what this hope is based on (Bloeser & Stahl 2017). Indeed, it is the redemption view through Christ that has driven the basis of Christian political reform, whereby punishment is not solely linked with proportionality of the crime but also towards restoration of the individual criminal, purely because hope is present (Kempshall 2003). Aquinas also examines everyday ordinary hope, seeing it as a passion which drives forward actions in his account in Summa theologiae (Lamb 2016) while at the same time being based upon a rational faith. In this way, hope can seen intrinsically connected to faith and love, stemming from rationality of knowledge, passion of belief and facilitating action.

4.2.3 Seventeenth and eighteenth century view of hope

During this period the majority of philosophers saw hope as a passion operating from within which could motivate either a rational or irrational action. This is true of Descartes, who in Passions of the Soul, (1649) saw hope as a weaker form of confidence where one would tend to think of an event as likely but not a certainty (Bloeser & Stahl 2017). It is this element of uncertainty that introduces anxiety and in this way hope and anxiety can often accompany one another. Thomas Hobbes saw hope as a cognitive process which meant that because it is bound up with our thinking, this can also play a part in deliberation (Bobier 2017). Spinoza failed to see hope as a rational process, seeing it as fundamentally irrational false belief and went so far to argue in *Ethics* (Spinoza 1677) that it was one of the causes of superstition (Bloeser & Stahl 2017). Hope, he argued was always caught up with fear rather than just anxiety and was why we should try to free ourselves from the desire for hope. Hume also views hope as a passion which comes about when the mind weighs up probable events that have absolute certainty and absolute impossibility. In the weighing up of events the mind can entertain contrary viewpoints of hope or fear which give rise to joy or sorrow. These feelings can persist and can affect the perception of the actual outcome.

Immanuel Kant makes a connection between hope, reason and judgement in his works, Critique of Pure Reason and Critique of the Power of Judgement where he grapples with fundamental questions of what can be known and what may be hoped for and what should be done (Beylevard & Ziche 2015). Kant's view of hope connects with moral action and decision making which is rational but is also connected with his belief in God. The hope of an immortal life goes beyond all that is seen in the suffering of this life and, to Kant, reason makes immortality necessary. Yet critics of Kant believe that hope is an attitude that can be

independent from faith and that hope provides a reason for belief, themes that have been echoed before in the previous section (Bloeser & Stahl 2017).

4.2.4 A post-Kantian and Existential view of hope

Kant's contribution to metaphysics, epistemology, ethics and aesthetics led him to be one of the most influential philosophers in Western philosophy. His significance was such that the period following after was referenced as post-Kantian. There appear to be two distinct views of hope in post-Kantian philosophy. Kierkegaard and Marcel view hope as a means to overcome the limits of ordinary experience and Schopenhauer, Nietzsche and Camus see hope as an expression of a misguided relationship to the world therefore querying its value. (Bloeser & Stahl 2017). Kierkegaard seems to distinguish between heavenly or eternal hope with an earthly or temporal hope, appearing to equate an eternal view of hope within a Christian tradition (Fremstedal 2012). Cutcliffe and Herth (2002), I believe mistakenly, look to Kierkegaard's definition of faith to suggest that Kierkegaard does not see that eternal salvation could be secured. However, Kierkegaard's acknowledgement that faith is the antithesis of reason, does not mean, in itself, that an eternal hope does not exist. An earthly hope is framed by an understanding according to its probability, whereas an eternal hope exceeds understanding, representing a nuanced difference from Kant's reasoned view of eternal hope.

In contrast Schopenhauer, understands that it is natural for humans to want to hope but believed it is something we should do less of as too much hope may make it impossible to grasp things are relevant to consider in an assessment of a situation (Bloeser & Stahl 2017). Hope can lead to disappointment when the outcome is not realised but it can even cause disappointment when it is realised in that it may not have created as much satisfaction than was previously anticipated. Colloquially speaking, this 'grass is greener' notion is well recognised. Nietzche is similarly critical of his view of hope. When interpreting Pandora's myth, in *Human, All Too Human* (1878) he calls hope as the worst of all evils because it prolongs the torments of man (Averill & Sandararajan 2015). For Nietsche, reasonable hope is a trust in an individual's capacity to bring about a desired outcome. However, while this may work in certain areas of life, how individual effort will bring about a desired outcome in circumstances beyond our control, such as life threatening illness, is less clear. Albert Camus is equally clear about his mistrust of hope, particularly hope in an afterlife esteeming the viewpoint that we do not need hope to cope with the hardships of life and death (Moeller

1958). Death should be seen as an absurdity but that that should not take us away from the enjoyment of the here and now. Interestingly, despite Camus's negative view of hope, he still states that it is almost impossible to live without hope even if one wishes to rid themselves of it (Bloeser & Stahl 2017). Is hope therefore something so internal and deep rooted as suggested by the opening lines of Emily Dickinson's poem at the start of this chapter, that it is etched in our very makeup? What is apparent is that in all of these accounts of hope from ancient times to existentialism, there is a constant ebb and flow of negative aspects of hope and positive components that have helped shape our thinking today in everyday life from the less pressing situations to the more pertinent. Having looked at the origins of hope, the next section will briefly look at two main theories of hope theory, before looking at the role of hope in nursing.

4.3 Key modern theories of hope

It is important to note that while there are a number of hope theories, there are two modern theories that have gained significance in understanding how hope is utilised in life and are of direct relevance to this study, the first from the field of psychology and the second borne within nursing science. The first is Snyder's hope theory (Snyder 2000) which argues that hope should be viewed as a cognitive skill rather than purely a reactive emotion whereby an individual shows ability to motivate towards a specific goal. The second is Herth's theory of hope which deals more specifically with an individual's future goals as they relate to coping with illness (Herth 2000). Both have a distinctively different feel and focus from the philosophy previously discussed, but both see hope as a positive and often goal related force. Both have relevance to considering how hope can be part of the fabric of caring for those patients who are potentially eligible for liver resection.

4.3.1 Snyder's hope theory

Charles Snyder, an American psychologist has been hugely influential in shaping a collective understanding of hope and in contributing to theory development. Snyder admits that the concept of hope and how it lends itself to be utilised throughout the life cycle, has been a concept that has fascinated him endlessly, much even to the bemusement of his wider family circle (Snyder 2000). His evolution of hope theory stemmed back from the mid 1980s when he was researching how people make excuses when they perform badly or make mistakes (Snyder, Higgins & Stucky 2005). Through this research Snyder found that the converse side of excuse making was a motive about achieving goals. This led Snyder to think about hope as

a mechanism for achieving goals and from there he went onto publishing his first article on hope (Snyder 1989). In developing his theory, Snyder had reviewed motivational literature of the 1960s and 1970s which looked at an individual's desire to set goals and was struck by the idea of hope as a motivational factor in goal setting from work such as Cantril, Farber, Frank and Stotland (Snyder 2000). While he identified with this work, Snyder felt there was something missing from the explanation of hope as a motivational factor. Much discussion about hope had seen hope spring from a feeling, something which can be understood from the previous sections on the history of hope. Snyder believed that the missing element was to place thinking at the heart of understanding hope rather than feelings or emotions. Someway towards defining hope, Snyder concluded,

> *"Hope as I was coming to define it, was primarily a way of thinking, with feelings playing an important, albeit contributory role" (Snyder 2002, p.249).*

Perhaps in this way, hope when viewed as a cognitive process, is not seen as an emotional reaction purely for the purposes of just being optimistic or hopeful but is actually a state of mind which can be used to drive forward intentions. Again, this can be linked back to historical concepts of hope as viewed theologically, whereby hope was a reasonable hope, considered and rationalised by the mind. It is this element of hope that can be both intriguing and attractive. The rational nature of attaching thought as the driving element of hope means that it less disposed to use emotion purely as a driving mechanism which could more easily lead to unrealistic expectations of hope. Within the context of patients being considered for liver resection for CRLM, particularly where the nature of that pathway can rapidly change (as referred to in Chapter Three), then the need to view hope as reasoned is one that can be argued to have value both to the clinician and the patient.

With the basis of human actions being goal related, Snyder postulated that we use routes or pathways to plan these goals and then attach a motivational force to carry them out. Research on hope and goal direction eventually led to a definition of hope in 1991 by Snyder and his colleagues as,

> *"Hope is a positive motivational state that is based on an interactively derived sense of successful (a) agency (goal-directed energy) and (b) pathways (planning to meet goals)" (Snyder, Irving & Anderson 1991, p.287).*

Snyder (2000) also defined hope as,

"the sum of perceived capabilities to produce routes to desired goals, along with the perceived motivation to use those routes" (Snyder 2002).

In either definition three clear elements of hope are identified, goals, pathways and agency. Hopeful thinking combines both pathways and agency thought. Snyder describes goals as the anchors of hope theory as they provide direction, categorising goals into positive goal outcomes and negative goal outcomes and also maintenance and enhancement goals. Maintenance goals refer to goal directed thoughts that are concerned with the everyday goals of living whereas enhancement goals are those thought processes which involve bettering of a situation that has some degree of profoundness or weight to an individual's life. What is interesting is that Snyder had changed his views on how much certainty needed to be attached to hope goals. He initially thought that hope was only hope if it had some perceived uncertainty, i.e. that having hope was not applicable if the probability of an event was extremely high or extremely low. However, Snyder reported that further research had shown that high-hope individuals had often injected some uncertainty into a goal situation that had seemed certain and conversely, had also altered their thought processes about seeming likely to fail situations in order to achieve what seemed like the impossible. These elements introduce that it is not just the event that is of question, but how an individual views their situation that can alter their sense of hope. This has immense relevance when dealing with individuals in clinical situations and is a reminder to withhold assumptions about goal attainment in health as they will be heavily influenced by an individual's personal trait and also their experience in that situation which may bear upon how they utilise hope. It can mean that one person might hear the same message as another person in a similar situation but react differently. It can also mean that two family members can hear the same information and interpret it differently due to their construct of hope.

The pathway component refers to the routes taken to achieve the goals and also the individual's perceived ability to produce these routes. It is the tendency of the human brain to work out goal pursuits from Point A to Point B. Put simply, hope involves the will to get there and different ways to get there (Kaufman 2011). Snyder again reports a difference in high-hope individuals, in that beyond the main route, high-hope individuals should be more apt at producing alternative routes to achieve the same goal. They also possess the flexibility to adapt their route, particularly when faced with impeding factors. The agency factor is the motivational agent available to bring about the goals. Synder describes this as the energy

required to start the route to bring about the goal. He reveals that it takes on a special significance when people encounter blockages, as the motivation can help channel energy towards the next best alternative route. A fourth component of Synder's hope theory, inferred to by its lack of absence in the definition are barriers. Barriers or obstacles block achieving goals by either making the individual give up or reinvent new pathways in order to attain the goal. Certainly, Snyder (2002) found that positive emotions can more easily overcome barriers, and work by Diener (1984) found that goal blockages are more often related to negative emotions. However, this may not always be the case as there may be times when having positive emotions may not lead to goal attainment. For example, one might feel positively about getting to a liver resection but the nature of liver disease after chemotherapy might make the liver inoperable. Positive emotions may in this case become a barrier to adjustment to the new state of disease. Certainly, Synder's work utilises hope as a mechanism in current psychotherapy whereby a therapist will help an individual to identify and work on barriers which may impede success in achieving goal attainment. Clients are enabled to set realistic and specific goals while being mindful of the ability required to achieve goals along with identifying the most appropriate pathways to achieve set goals.

Whilst high hope individuals have been found to correlate with some beneficial constructs, such as academic achievement (Snyder et al 2002) and lower levels of depression (Snyder 2004), the popular adage 'think positive', may also have a few problems. The belief in the power of positive thinking is so common place that one might think that it could eliminate negativity and change the course of illness. Yet, what we see in life, is something very different. Research on weight loss led by Oettingen (Oettingen & Wadden 1991) found that women who were asked to employ positive thinking to visualise successful weight loss actually lost less weight than their counterparts who also had negative pessimistic expectations of weight loss to consider. They found that expectation and fantasy thinking produced different results which at first seemed counter intuitive. This was later replicated by Kappes et al 2011 when they conducted a similar exercise with college students. In this Oettingen concluded that,

> *"dreaming about the future calms you down, measurably reducing systolic blood pressure, but it also can drain you of the energy you need to take action in pursuit of your goals" (Oettingen 2015).*

What Oettingen proposes instead is something called 'mental contrasting' which is an approach to positive thinking but taking the realism and pragmatism usually present in

negative thinking. Oettingen breaks mental contrasting into four steps that are easily remembered and applicable to challenging situations. They fit into an acronym know as WOOP and enable the individual to mentally confront the situation by visualising their desired result but together naming the realistic obstacles in way of the desired outcome. The first step is WISH where time is taken to identify a wish regarding the situation that is realistic and challenging. When compared to Snyder's work, this would be known as what we commonly call goals. The second step is to identify the OUTCOME, where the best possible consequences of this wish would come true and visualising the feeling that would create. The third step is to identify the OBSTACLE or obstacles standing in the way of the wish. The idea here is that they are given appropriate time and not shied away from with a cursory mention but envisioned with the same degree of thought and energy as the positive outcomes have been given. In this way it the pragmatism comes in and the mind begins to acknowledge the complete reality of the situation. The fourth step is the PLAN which is about stating a way for success to be achieved which is specific and realistic. This is akin to Synder's pathway in his hope theory model. While some of this may sound quite simplistic, studies have shown that there is a distinct difference in positive thinking without taking in the approach used in mental contrasting. People using mental contrasting were found to exercise more (Stadler et al 2009), have a higher nutritional intake, (Stadler et al 2010), cultivate healthier relationships (Houssais et al 2013) and even recover from chronic back pain quicker than compared to positive thinkers alone (Christiansen et al 2010). This may be because they factored in the risk of not doing a certain behaviour. It would seem that there are different types of positive thinking; fantasising which may do more harm than good and mental contrasting which takes in aspects of negative thinking that may be more effective in helping wishes or goals become actualised. Criticisms of this form of positive thinking may be that it only tackles one kind of goal, such as a goal that requires commitment like weight loss or working for a qualification. What of those situations, where the result is not solely up to the individual such as goals in health as clearly depicted in the pathway to CRLM? Kaye Herth's work on hope in health care situations is especially relevant to consider.

4.3.2 Herth's contribution to hope theory in health

Whereas Synder's theory focuses on utilising hope as a mechanism to overcome lack of motivation, another major theory as developed by Kaye Herth relates to how an individual constructs goals amid illness. Much of Herth's lifetime research has focused on hope in

individuals with a chronic or terminal illness and the impact on their families and significant others as well as research on homeless families and children. Herth's doctorate work in 1982 with cancer patients became the spark to examine hope and contribute towards development of hope theory and a tool for measuring hope, named the Herth Hope Index (1994). Herth became particularly interested in how hope was maintained when events were not entirely constrained by ones own motivational force. This has parallels with the idea expressed by Gadamer in Truth and Method (Gadamer 2013) at the opening section of this chapter whereby his interest lay with what happens when life is above our control. In such situations, Herth recognises that maintaining realistic goals is more difficult as the individual is less likely to have direct control, for example as is often evident in health. Hearth sees hope as a

> *"motivational and cognitive attribute that is theoretically necessary to initiate and sustain action toward goal attainment" (Herth 2000).*

Much of Herth's work aligns itself with Marcel's existential viewpoint that human beings have an endless possibility of improving their own being or that there is something inherent in them that that causes hope. This allows them to adjust goals from mastering and defeating an illness, which may not necessarily resolve, to being concerned with how to deal personally with the illness itself. Herth (2000) provides the example of someone with a chronic illness deciding not to use alcohol as a way of easing the pain of illness but instead choosing to surround themselves with friends and family. There is a strong cognitive element where decision making is closely influenced by individual hope, but not of a general hope for health resolution or cure but for specific hopes along the way while living with illness. Decision making becomes influenced by personal hope but also hope fuels decision making and a cyclical process, can become apparent. Whilst the nature of the goals in Herth's model differ with those in Synder's model, they both view hope as a way to maintain personal motivation. Adopting a combination of these models can perhaps avoid some of the pitfalls as described by Oettingen (2015) regarding optimism.

4.4 Examining the role of hope in nursing

There is now a growing body of literature which would suggest that nurses can utilise and help apply the concept of hope in a therapeutic approach with individuals and their families facing periods of ill-health. Masera (2010) points out that the meaning and significance of hope for individuals will depend upon an individual's life circumstances and how their

personal philosophical stance shapes that hope. Perhaps for this reason, Masera (2010) alludes to the challenge that bringing hope into difficult health situations may have for nurses.

> *"Instilling hope is a major task for nurses in situations of distress, discomfort, inadequacy and dependency" (Masera 2010, p.69).*

Any nursing environment will immediately reveal many threats to hope. Masera (2010) identifies these as pain, uncontrolled symptoms, spiritual distress, fatigue, anxiety, social isolation and loneliness. Masera also identifies that external threats of perceptions of hopelessness from health professionals and family can also attack personal hope. This is important to consider as this sense of hopelessness from others may well be communicated strongly through language and by non-verbal communication but may have a powerful eroding effect of personal hope. Masera (2010) also senses that this may well be the context of modern medicine where there is much focus on cure but not care. In so doing, Masera (2010) revisits Jean Watson's theory of human caring, originally developed in 1979 but with subsequent revisions, as somewhat of an antidote to what could be a very imbalanced view of care if it was only attached to cure. Among ten constructs of caring in nursing, hope is listed as one of them. The context to the development of this theory during the late seventies/earlier eighties was that care did not get lost while changes in healthcare delivery systems were intensifying nursing responsibilities and workloads. As developments in medicine continue apace it is always worth pausing to ensure that hope as part of the wider context of care does not get suppressed even in those situations where cure is no longer evident.

Cutcliffe & Herth (2012) offer a logical sequence of steps for examining the nature, origin and background of hope in nursing literature as set out in Table 4.1. overleaf. Much of this relates to the account in section 4.1 but it is worth briefly revisiting this from their viewpoint. They begin by examining the theological and philosophical origins and background of hope as listed in steps 1 and 2 and cover Chinese, East Indian, Ancient Greek, Christian and Existential perspectives. Their brief overview concludes that there is no direct reference to hope from a Chinese or East Indian perspective and that from an Ancient Grecian perspective, Hippocrates alludes to the concept of hope but does not explore the process of hope.

Logical sequence of steps for examining the nature, origin and background of hope	
Step 1:	What is the origin of hope and does the theological literature allude to this origin?
Step 2:	What is the philosophical background of hope?
Step 3:	When and in what manner did hope begin to be considered within healthcare literature?
Step 4:	What definitions of hope are there in the theoretical and empirical healthcare literature?
Step 5:	What are the key themes of hope that are evident in these definitions?
Step 6:	Do these definitions and their inter-relations provide an indication of the elements of hope and hoping that appear to be implicit in the literature?

Table 4.1: Cutcliffe & Herth's (2012) sequence for examining hope

Cutliffe & Herth (2012) feel there is merit in examining the existential perspective also as it shares some commonalities of the Christian perspective but from a counter position. Both Nietzsche and Sartre advocated that as man becomes more aware of his existence over time he can almost become more aware of the absurdity of his existence and the sense of despair that accompanies those sentiments (Thompson 2008). This position tends to suggest that life itself carries no meaning and indeed if faith in God cannot be proven then hope may be unreasonable. However, as already seen, there may not be any visible evidence for the hope that people have, especially when it may not correlate to a physical state of health. To counter the existential perspective, Marcel (1948) sees that if we can function in a finite world and influence our existence then at some micro level we are able to make a difference in our community and assert change (Greenaway 2018). This leads to a more positive view of the world and reinstates meaning, which for some existential philosophers is more closely aligned with the Christian perspective. Therefore, a hope for future outcomes that do not yet exist share more parallel links with possessing faith and are often linked to human and spiritual existence, even if individuals may not possess a faith belief as such (Cutcliffe & Herth 2002). Drawing on the work of Hinds (1984) in defining hope and Raleigh (1992) with identifying sources of hope in chronic illness, they write,

"To the person who has hope and who experiences a sense of hopefulness, it is the most logical, sensible thing. If hope provides one with a sense that one has a future, and also enables one to cope with events in the present, then (if one wishes to preserve one's existence) it is a logical state of being." (Cutcliffe & Herth 2002, p.835).

4.4.1 Hope in nursing literature

Much of the literature in nursing stems from observations or studies with cancer patients. An early study by DuFault & Martoocchio (1985) collected qualitative data among 35 elderly patients with cancer and then 47 terminally ill patients. While the methods of data collection and analysis are not made transparent, their early study was a good starting point from which to look at hope in cancer. They revealed two spheres of hope, a generalised hope which was broad in outlook and a particularised hope which was related to a specific outcome. They also described six dimensions of hope which could belong to either sphere of hope; affective, cognitive, behavioural, affiliative, temporal and contextual. This work perhaps looked more at the structural components of hope and is more theoretical in nature than helping to reveal concepts that are readily translated into practice.

Using grounded theory, Owen (1989) induced a conceptual model of hope from his study in which he collated clinical nurse specialists' perceptions of hope in their patients. While it is unusual to look at perceptions of hope as viewed through the eyes of someone else, the study does give a worthwhile angle because of the positioning and intensity of contact of the nurse specialist across a spectrum of a patient's illness journey. Six themes were elicited from the study and are outlined in Table 4.2. overleaf. They help to give a workable list of attributes of what hope looks like in practice.

Certainly, it may not be necessary or possible for an individual to possess all of these aspects at one time but the themes identified are concepts which resonate with the overwhelming sentiment, that hope is positive. Hammer et al (2009) state that despite the lack of consensus as to the attributes of hope, that hope has a positive role in human life and is both universal and specific. It is universal in that it is a general belief in the future and a defence against possible despair but it is also specific and directed to an event or object. Perhaps this idea of a defence against despair is an element worth noting and one with which Morse and Doberneck's (1995) study resonates with the third of their seven universal components of hope as seen in Table 4.3, also overleaf.

The six themes in Owen's (1989) conceptual model of hope	
Goal setting:	Hopeful patients engaged in setting (and revising) attainable goals. It may be worth noting that the goals of these patients noticeably changed as death approached (e.g. smaller, more attainable, and more realistic)
Positive personal attributes:	Hopeful patients were described as having several hopeful personally characteristics (e.g. courage, optimism and a positive attitude)
Future redefinition:	Hopeful patients were described as those who saw or perceived the future, and this future was not quantified in time
Meaning in life:	Hopeful patients were those who equated hope with a meaningful life
Peace:	Hopeful patients were described as being at peace or comfortable with their situation
Energy:	Hopeful patients were described as being those who possessed and gave out energy. Additionally, Owen reported that the hopeful patient needed energy to remain hopeful, hope required energy and gave energy

Table 4.2: Owen's (1989) conceptual model of hope

Seven abstract and universal components of hope
A realistic initial assessment of the predicament or threat
The envisioning of alternatives and the setting of goals
A bracing for negative outcomes
A realistic assessment of personal resources and of external conditions and resources
The socialisation of mutually supportive relationships
The continuous evaluation for signs that reinforce the selected goals
A determination to endure

Table 4.3. Morse and Doberneck's (1995) seven abstract and universal components of hope

These attributes also bring into play the community aspect of hope when Morse and Doberneck refer to seeking external help through mutually supportive relationships in component five and in taking stock of what personal resources they have to equip them

during this period in number four. This combined with personal review of signs that their goals are being met, has introduced a more reflective and supportive view of hope. In addition to a positive focus, Morse and Doberneck's (1995) work also introduces the idea that factoring in negative outcomes are all part of hope in that they suggest it is healthy to be prepared for a negative outcome, one that was different to what was hoped for in component three. Haarse and et (2002) also identify with a potentially negative sentiment in their attributes of hope, that of uncertainty. One of the perplexing features about hope, is the element of uncertainty. It is of course that only while there is uncertainty, can there be hope. Haarse et al (2002) define hope as

> *"an energised mental state involving feelings of uncertainty or uneasiness which is characterised by a cognitive action oriented expectation that a positive future goal or result is possible" (Haarse et al 2002).*

Despite uncertainty, hope is known as a positive state and this quote suggests that it is one that is required to be realistic in expectation as it can be utilised to achieve goals that are potentially possible.

Yet hope is fluid, adaptive and responsive and so as a result goals have to be reset and the future redefined as Owen (1989) has suggested in his conceptual model of hope in Table 2. A common theme in the nursing hope literature is that there is a changing hope trajectory across an illness period. Herth (2018) recognises this illness trajectory and it is easily identifiable in chronic illness and terminal illness. Colquhoun & Hill (2011) note in cancer literature, that the nature of hope changes from that of diagnosis to treatment and should cancer progress, hope will change through a palliative phase. Sanders et al (2012) define the hope trajectory in cancer as

> "the state of desiring an identified possible event or future outcome, which then becomes the hope object. The hope trajectory is the changing pattern the hope object takes as the cancer progresses" (Sanders et al 2012, p.241).

This may be especially seen when the object of hope is no longer cure and the hope object needs to change to a realistic hope. Setting realistic goals has become an important aspect of personalised care in the palliative care setting (Colquhoun & Hill 2011). Sanders et al (2012)

drawing upon Nurgat et al's (2005) work involving patients' motivations to take part in clinical trials, write that most individuals manage to make transitions within their disease, using a realistic hope. Evidence would suggest that there are many patients who remain hopeful right up to the end of life despite a terminal diagnosis or illness period (McIntyre & Chaplin 2007) and manage successfully to readjust their goals. This may point back to the characteristic of the universality of hope, i.e. that there is something inside of us as humans to causes us to hope. There are, however, some patients who cannot revise their hope object and persist in an unrealistic hope trajectory. In this instance the hope object becomes maladaptive and can create potential communication difficulties, not just for the patient but also for their families and healthcare team. An interesting paper by Pergert & Lutzen (2012) suggest that in such cases where patients wish to hold onto an unrealistic hope that a tempering of the truth may occur by the healthcare team in order to protect the patient's view of hope. This may be especially tempting when the disease progression is rapid and the patient may not be showing readiness to understand the reality of their disease since the diagnosis period has merged with progression. Doing so may actually cause further emotional difficulties for the patient as time goes on into the patient's illness. Pergert & Lutzen (2012) argue that,

> *"To suggest that hope is versus truth or that hope needs to be balanced with honesty/truthfulness may distort you to believe that truth and hope are irreconcilable dichotomies. On the contrary, truth telling has been found to support hope." (Pergert & Lutzen, 2012, p.24)*

Some factors may act as threats to hope and may well cause an individual to have an unrealistic hope. Miller (2007) outlines the following factors, one's life philosophy and the meaning that one attaches to events, a sense of optimism and any personal or spiritual beliefs. Colquhoun & Hill (2011) also identify not feeling valued as a person, having a sense of abandonment or isolation and very importantly poor symptom control. There may also be other factors which greatly influence hope as specific to a cancer situation, such as personal experience of family cancer in the past.

4.4.2. Role of the nurse in fostering hope

Nweze et al (2013) report that there is increasing evidence to show that nurses have a role in facilitating hope. Randall & Downie (2006) are quick to point out that while nurses can

have a role in fostering hope, the hope belongs to the patient, and they are the origins of their hope. It is not our hope.

> *"Whilst we ought to encourage people to hope for outcomes which are probable, and to help them adjust away from hopes for the extremely unlikely, at the same time we ought not to seek to control their hopes"*
> *Randall & Downie (2006, p210.)*

Nweze et al (2013) suggest that nurses may be well placed to offer hope due to their constant interaction with patients in similar situations so that they have an understating of what can be achieved. This also feeds into the importance of trust in the nursing relationship, making it easier for the patient to set goals to be realised. Establishing and building upon trust from the outset of the patient nurse relationship is important and is likely to require highly developed communication and clinical judgement. The beginning of that relationship is often emotionally challenged set within the context of a diagnosis. This is evidenced in research by Cao et al (2017) who researched communication with doctors giving a diagnosis of cancer and how that affected trust and hope in patients. A number of factors can affect how the initial diagnosis consultation can be perceived and recalled by the patient. Clinical presentation and the absence of symptoms may make it particularly difficult to absorb and recognise that the information discussed pertains to them. Working within this sector, episodes can be recalled where diagnosis information is not well received by the recipient due to emotions of anger and distress. How unfavourable bad news may be, how it is communicated has shown to influence patients' treatment decisions, adjustment, well-being and in some cases survival (Ptacek et al 1996, Fallowfield & Jenkins 2004, Sastre et al 2011). This should not perhaps be surprising, when we consider the central issue of trust at stake when making significant health and treatment decisions.

Indeed, this very aspect, touches on the centrality of caring for individuals rather than treating the disease. Cao et al (2017) recognised how adverse communication could be hard to turn around but the study contained little in the way of what constituted effective disclosure which opened up aspects of hope and was closely linked to trust. Cao et al's study (2017) is based in China and they acknowledge that although Asian medical systems are now under the same pressures as Western countries, in delivering a wider range of treatments amid time constraints while meeting targeted goals, they realise that Asia in general is still facing a disclosure dilemma, something which Western countries have for the most part resolved. They state that Asian doctors are trying to move away from restricted patient

disclosure due to cultural, often family led protective mechanisms at work and become more like Western countries who have shed any of these approaches; consulting the family first before the patient, providing no disclosure, ambiguous disclosure or false disclosure (Kakai 2002).

Cao et al's (2017) quantitative study utilised a specifically devised and tested questionnaire in addition to the validated Herth hope instrument and Wake Forest physician trust scale to assess 192 patients at a major university teaching hospital, the majority having had a diagnosis of lung cancer or breast cancer. Perceived emotional support from doctors was positively (but not significantly) associated with levels of trust and significantly associated with hope in doctors. The one striking feature of this study was that on the questionnaire, the word 'disease' was used instead of 'cancer'. One might argue that although, all patients were eligible as they knew they had cancer, this might also influence how patients responded to the hope scale. The decision may have been based on the author's reference to Farber et al's (2002) study, which found that after clear disclosure of cancer to a patient, patients did not want the word reiterated at every stage. The study has implications in that throughout a period of elongated treatment and decision making, such as in CRLM, emotional support would appear to be key. Often in this setting, it is the nurse specialist who in addition to the medical professionals, are able to provide this support, often based over a longer continuum of a patient professional relationship. This relationship may also be key in addressing situations where hope related to treatment is not achievable due to disease progression, technical feasibility or patient health.

The idea that disclosure of honest information or prognosis is harmful and suppresses hope can no longer be viewed as helpful. This is evident in practice and can led to lack of preparation for the next stage of disease or even death. This is supported by an American surgical literature review by Winner et al (2017) who concluded that enhanced preoperative surgical discussion could maintain hope even if the topic is a bad prognosis or eventual death. From the literature reviewed, hope was often seen as optimism in relation to prognosis. This corresponds with the section relating to Snyder's hope theory (section 4.2.1) where some of the difficulties of optimism were discussed. This has the tendency to create a singular hope whereas honest, patient-driven discussions could still allow for hope in other areas such as cancer recurrence, preferences of care and also future planning. Winner et al (2017) identified four main themes whereby patient-surgeon communication could fail: 1) a lack of

clarity perpetuating prognostic misperception, 2) prognostic discussions proving emotionally challenging, 3) patient's suspension of belief and 4) information largely thought to be antithetical. The overall key, Winner and colleagues feel, is that both surgeon and patient need the opportunity to articulate their goals and expected roles in the decision making process. In response to these communication failings evidenced in surgical literature, Winner et al (2017) suggest practical considerations to facilitate hope which are not just focused around prognosis. They suggest that clinicians need to know what kind of communicators they are, to examine failings such as relying on euphemisms, rushing over uncomfortable areas or failing to evoke feedback on information received. They also suggest that surgeons should not assume they know what patients want to hear, appreciating that a patient may not rationalise information or decisions about surgery in the same way. Other suggestions include, emphasising the choice of treatments and the range of therapeutic goals, which are not just surgical removal of the cancer, prescribing 'homework' for patients, whereby they allow time for discussion at home with significant others about choices and preferences, finding time for further discussion if needed or enabling others to have these discussions. Importantly, they also suggest that clinicians should not be afraid of realism or discussing non-curative goals.

Moving away from hope seen as solely as cure can also allow for focus on other important issues such as, achievement of life events, relief of pain, maintaining independence resolving outstanding issues and even preparing for death. Allowing for this draws upon Snyder's achievement orientated view of hope, with the use of pathways to allow for achievable goal setting. Although Winner et al's (2017) paper focused on the surgeon's role primarily in leading these consultations, there is much for the nurse specialist here, being well placed between surgical and oncology teams to facilitate discussions in a less time restricted manner. This contact may open up the concept of hope into other areas thereby moving it away from purely a cure or surgically driven hope. This paper has considerable relevance considered in the context of surgical resection of liver metastases, where the ultimate goal of that pathway is to achieve surgery albeit that may not always be achievable. Focusing on additional hopes throughout that pathway are particularly relevant and require a specific set of communication skills, which the nurse specialist is well placed to bring to the cancer team.

Other authors have identified a number of strategies for maintaining hope, in addition to ensuring physical needs are met, which require advanced communication skills as indicated

by Winner et al (2017). Colquhoun & Hill (2011) highlight a number of key strategies or interventions which nurses can use to sustain hope as shown in Box 4.1.

Key strategies for sustaining hope

- Maintaining the patient's physical comfort
- Supporting meaningful relationships with family and the healthcare team
- Ensuring that the patient and family feel valued as individuals
- Encouraging the patient to identify and achieve important aims
- Enabling the patient and family to retain choice and control
- Promoting reflection on life and creating meaning and legacy
- Providing opportunities for spiritual quest, expression and growth
- Using light-heartedness and humour appropriately

Box 4.1: Key strategies for sustaining hope, Colquhoun & Hill (2011)

A further aspect to consider which is not noted here is signposting patients to others to help meet queries or concerns. If nurses are to facilitate hope in others then Morse & Doberneck (1995) suggests that they should have a high degree of self awareness and an understanding of what they look to for hope themselves. As much of this work may be emotionally demanding for the nurse, nurses may benefit from adequate support mechanisms for themselves in the workplace.

4.5 Hope in colorectal cancer literature

In the absence of any papers directly concerned with hope in those with potentially resectable liver metastases, it is worth looking at literature referring to hope in colorectal cancer. One study has direct relevance, seeing hope as a critical factor rather than a vague by-product of care. Beckman et al (2013) brought this to bear when they interviewed ten patients with advanced colorectal cancer in order to explore by thematic analysis what the content of hope was in these patients. Their four themes revealed that (1) hope was essential, (2) involved a change in perspective, (3) had a specific content and (4) required communication. Themes 1, 2 and 4 while rich in data themselves are more self explanatory. The third theme is of particular interest because it unpacks three sub-themes in the content

of hope. These are the desire for normalcy, future plans and a continued hope for cure. At first glance these are themes that one would understand to sit comfortably within the context of potentially curable disease. Yet, Beckman et al (2013) were quick to point out that they had included patients with advanced disease who both had potentially curable and incurable disease as they wanted to examine the role of hope independent of hoping for a cure.

Indeed, this sentiment is picked up by Weeks et al (2012) whose study of patients understanding of the rationale for chemotherapy in advanced cancer, had found that despite often being told that disease was not treatable, adults still hoped for a cure. This also corresponds with the idea that hope is embedded within and is hard to suppress, as the reference to Emily Dickinson's literature at the beginning of Chapter 3 suggests. Arthur Frank's (2014) personal revelations when his mother was dying powerfully convey this sentiment. He recalls his father focusing on the normalcy of that life that they used to know, still expressing that his wife could get back to this life if only she could get her strength up. Such responses are regularly evident in the clinical setting. Very often, the expression of normalcy, future plans and continued hope for cure may co-exist. This does not mean that the patient is in denial, an aspect which will be discussed further in Chapter 9.

4.6 Chapter summary

To summarise, hope can be adopted in all stages of the cancer trajectory. As Saeteren et al (2011) write a cancer diagnosis is

> *"an existential upheaval which takes the patients through demanding phases filled with contradictory emotions and uncertainty" (Saeteren et al 2011, p.811.)*

Hope gives direction, purpose and meaning and helps to secure achievable goals yet when those goals are no longer possible, hope reacts flexibly to readjust goals. Continued advances in treatment are pushing the boundaries of what was commonly expected in the management of colorectal cancer liver metastases. To comprehend that liver metastases might be rendered operable and completely resected provides another interesting avenue to study the role of hope and furthermore, how hope can be fostered in this context.

Chapter 5

From Musings to Method

"What man needs is not just the persistent posing of ultimate questions, but the sense of what is feasible, what is possible, what is correct, here and now. The philosopher, of all people, must, I think, be aware of the tension between what he claims to achieve and the reality in which he finds himself." (Gadamer 2013, p.xxxv).

5.1 Chapter overview

This chapter will focus on the chosen research methodology and method adopted for this study. In so doing, it will set out the chosen processes behind the study and the tools used in conducting the study to answer the study questions. The chapter itself tells something of the story of my journey as a researcher, as it details the initial thinking about the study area, conceptualisation of appropriate research design and determining practical considerations in order to provide functional procedure. The chapter also explains the relevance of choosing a theoretical framework suitable to this qualitative study as a hermeneutic phenomenological approach and introduces the key figures instrumental in the phenomenological movement before introducing Gadamer whose philosophy has more particularly influenced this study. My position to this study and setting is also examined, having that of an insider-outsider position as both researcher and practitioner within this environment. Adopting a reflexive approach has been critical to the study and one, in which I believe, sits alongside Gadamerian phenomenology in that it also provides another 'fusion of horizons'. Finally, issues of rigour and adoption of analysis are discussed.

5.2 Research journey

Before deciding to undertake this study, I remember others who had encouraged me to commit to my intended research subject for the journey it would present. Initially my thoughts were not necessarily on the journey that I would encounter as a researcher but on hearing and giving voice to the experiences of those on the colorectal resection pathway. My hope was that by so doing, that these experiences could be utilised to improve that pathway to create a tangible benefit to patients being considered for liver resection. Nonetheless, on the surface, 'the journey' sounded intriguing and hinted at being rewarding. The reality is that journeys are made up of many ups and downs on the way, a sentiment that is echoed in MacKenzie & Ling's (2009), wittily entitled paper 'The research journey: A *Lonely Planet*

Approach'. As with all journeys, it is only towards the end of that journey, that one gains perspective from where they have been and how far they had travelled, both personally and pragmatically. At the outset of the research journey, I grappled with how best to design the study and what methodology might be more appropriate. Funding provided, through a local NHS Foundation Grant, had an associated ethos of service improvement. This gave the research a pragmatic focus and early thoughts regarding methodology learned towards action research which could be easily understood against the context of the cyclical nature of evaluating a service, reviewing and then evaluating that service after changes were implemented. Action research generally follows a cyclical process of, plan act observe reflect replan (McDermott & McNiff 2016) and because of this has had general appeal in studies relating to social and political transformation (McNiff 2013). A guiding basis for action research as a methodology is the improvement of a situation and as Winter & Munn-Giddings (2001) suggest this carries an ethical value and "practical responsibility for others wellbeing" (p.220). While such values are worthy in themselves to conduct research, I still felt there could be something impersonal about utilising action research as a methodology. My intentions were firstly to understand and then to let the experiences of those being considered for liver resection drive forward a change. Although perhaps a subtle difference, my concern with action research alone, was that too much emphasis would be placed on the service alone rather than the people who encountered that service.

Further considerations were given as to whether a more longitudinal focus might work and lend itself to a mixed methods research, so that the use of quantitative data could lend an insight into quality of life experience at different timepoints in the wait for liver resection. This was rejected as the literature and also observation suggested that the majority of people waiting for CRLM encounter few symptoms as discussed in Chapter 3. Finally, I also considered using focus groups throughout this study for patients as well as health professionals but again dismissed this as I was interested in not only a collective story but also the uniqueness of each person's story and I felt that that was harder to capture where patients were grouped together in focus groups.

Whilst ideas can be captured and reshaped in research, time gives no such luxury. The reality in research is that the clock is ticking from the moment funding commences. Time helpfully places boundaries around ideas but allows for focus of the original ideas of research design. In my case, this is what occurred and I was able to reflect on my original ideas to proceed

quickly to ethics application when the study funding commenced. My main concern was that the voice, the language, the very nature of 'being' considered for liver resection was heard and for this reason I decided upon hermeneutic phenomenological inquiry. The rationale and background for choosing this is discussed in section 5.4 and 5.5.

5.3 Ethical approval

The conduct of any research study relies heavily on guiding ethical principles. The most common way of defining ethics is based around norms of conduct that distinguish between acceptable and unacceptable behaviour (Resnik 2015). There is a pragmatic distinction between formal codes of conduct agreed by governing research bodies and the ability of the researcher to conduct themselves according to that guidance throughout the research study. Section 5.9.2 addresses how I sought to adopt ethical safeguards in the practice of this research study.

Formal ethical approval was sought and granted in December 2012 from the local Research and Ethics Committee (REC) and from local NHS and ACCORD Research and Development (R & D) Offices through the online Integrated Research Application System (IRAS) (https://www.myresearchproject.org.uk). This importantly, also allowed approval to access the study sample within three hospitals within a major teaching network. Working within the colorectal team, gaining physical access to participants was perhaps easier than coming in as an outside researcher but formal approval, while not only necessary, also ensured accountability despite being known as a member of that team. I endeavoured to conduct myself as researcher in the same professional manner that I adopted in everyday practice as a member of the colorectal team. Funding primarily provided by a local Health Foundation Fund and latterly by an oncology endowment fund allowed me to step out of normal practice and concentrate on the study for 3 years and 3 months. Ethical approval gave me the guiding principles to ensure that there was no harm to participants, informed consent was maintained, privacy was withheld and no deception with regard to participants or data took place as, outlined in early ethical principles by Diener & Crandall (1978). Strict adherence to the research inclusion/exclusion criteria was maintained for patient protection and study validity (Holloway & Wheeler 2002). Close multidisciplinary team working was in place to ensure that all patients were suitable to approach. The tone that I wished to set throughout the study was one of permissive inquiry, whereby it was clear to participants that they were consenting for use of their personal treatment stories to be heard and analysed and that I in

turn had to take care to honour the personal nature of their stories through careful interpretation, which in turn had the power to drive forward a change in service for future patients.

5.4 Research Design

The choice of study methodology discloses something about the researcher's view of reality and their commitment to guide the study alongside theoretical frameworks pertaining to that reality. A qualitative research paradigm has been chosen to answer the research questions in this study. This was deemed suitable following a review of the two research strategies which underpin medical and nursing research; quantitative and qualitative.

A quantitative paradigm focuses on the cause and effect relationship between variables and is concerned with measurement whereas qualitative research is predominantly focused on words and meaning (Weaver & Olsen 2006, Bryman 2016a). A quantitative research strategy is deductive seeking to test theory whereas qualitative research is inductive by nature seeking to generate theory (Malterud 2001, Bryman 2016a). Qualitative research has a particular strength in eliciting the commonly untold aspects of everyday or more complex human experiences (Bryman 2016a, Polit & Beck 2010, Tilley 2011). Unlike quantitative research, it can capture the depth of human emotion for a given situation or context.

The value and constraints of each can be understood when looking at each paradigm's own epistemological, ontological and methodological position which in turn frames how a study will be conducted (Cibangu 2010). Quantitative research adopts a positivist epistemological position which presumes that phenomena can be measured according to the practices of a natural science model whereas the epistemological position of qualitative research is interpretivism which emphasises the way in which individuals interpret their social world (Bryman 2016a). The ontological orientation for quantitative research arises from a view that social reality is objective. This is compared with a view of reality that is named constructionist in qualitative research, which supports the idea that reality is constructed or made sense of by an individual (Barab et al 2007).

A key methodology of interpretivism as displayed by qualitative research is phenomenology. Phenomenology as a research method is well suited for exploring people's life experiences (Parahoo 2014). Indeed Parahoo (2014) believes that phenomenology is well placed to explore patients' experiences of illness. As Simpson & Whyte (2006) outline, phenomenology

is linked to the ontological question 'What is being', which again is conducive to an exploratory study on patient experiences during illness.

Commonly, and inaccurately, methodology and method are frequently used interchangeably in qualitative research (Cram 2013). This has often led to confusion and a lack of clarity over which one is being referred to. For the purpose of clarity, the research method can be described as the tools, techniques or processes that are used to conduct the research whereas the research methodology is the study of that method or as Cram (2013) refers to "the principles that guide our research practices" (Cram 2013, para. 3). Any chosen research method should be conducive to the area to be studied and that method should be heavily influenced and shaped by underpinning methodology. Each should support and reflect the other and sit comfortably together.

5.4.1 Incorporating the insider-outsider (emic-etic) position into methodology

Importantly, time to undertake the research while not practising in my usual clinical role, allowed me a degree of distance from everyday clinical commitments. It also allowed me to adopt a sole researcher role with the added benefit of insider knowledge, without having any existing contact with the research participants. It may also have allowed the participants to speak about their experiences more freely, knowing that I had not been directly involved in their care. It is maintained that this position as researcher with insider knowledge was integral to both the design and analysis of the study. It gave a unique position and framework of understanding, having both practical implications, as mentioned above, and theoretical implications.

In ethnographic research, reference is often made to the 'etic' and 'emic' position. These terms were coined by the linguist, Kenneth Pike in 1954. Pike argued that linguistic tools, offering a certain position, could be adapted in order to understand social behaviours (Beals et al 2019). Emic is the view from within the social group and etic is that of the observer, i.e. outwith the social group to be studied (Lapan et al 2012, Zeegers & Barron 2015, Silverman 2017). I steered away from using these terms, directly seeing them to have greater value to ethnographic research. However, I could clearly see the emic-etic considerations in relation to how I positioned myself as researcher. Instead, I favoured the terms insider-outsider to reveal that I saw myself as an instrument of the research (Zeegers & Barron 2015), synonymous with having a bearing upon the method and resultant analysis. I was not an

insider in the sense that I had shared the same experience as the participants but that I had a pre-existing knowledge of the participants' world. Adopting the outsider position as solely researcher for this time and not that of my usual clinical role, allowed me to enter into the world of participant with no knowledge as to the specifics of their individual story. The aspect of insider-outsider lent a balance on the continuum of objectivity as a researcher, blending both positions. Perhaps conversely, the insider knowledge may have improved objectivity rather than hindered it, allowing interpretation of the participants' words to be weighed against a more complete understanding of the multi-factorial agents at work in the pathway to CRLM. This positioning also reflected the chosen methodology drawn from Gadamer's fusion of horizons as explained in section 5.5.3, whereby pre-existing knowledge is absorbed into and reflected on as part of the interpretative process.

5.5 Theoretical Framework

This section details the background to the chosen research method by providing a brief historical reference to the conception of hermeneutic phenomenology and its key attributes which make it relevant to the study drawing upon the influence of Gadamer and more recently van Manen.

5.5.1 Key figures in phenomenology

A key founder of phenomenology was Edmund Husserl (1859-1938) who developed his thinking on understanding conscious experience following his dissatisfaction with the natural science model adopted in positivism which he saw as inflexible to individual experiences (McConnell-Henry et al 2009). This was later applied to the social sciences by Alfred Schutz (1899-1959) who advocated the researcher to block out or 'bracket' their own preconceptions in order to gain a pure as form as possible of the participants' experience (Bryman 2016a). In contrast to this, Hermeneutical Phenomenology seeks to acknowledge the researcher's involvement in the making of and presentation of the data and in acknowledging any pre-existing judgements about the patient group (Taylor 2001). As the researcher has worked with the proposed patient group and intends to facilitate much of the study in face-to-face interviews, a hermeneutical phenomenology will be the preferred methodology for the patient experience work.

Each research paradigm has its own benefit when addressing different questions. By general comparison, in simple terms, quantitative research tends to focus on a cause and effect

relationship between two variables and is concerned with measurements, whereas qualitative research is predominantly concerned with words and meaning (Bryman 2016b). By nature, a quantitative research strategy is deductive, seeking to test theory, whereas qualitative research is inductive and seeks to generate theory (Malterud 2001, Bryman 2016a). The value and constraints of each can be understood when looking at each paradigm's own, epistemological and ontological position, which in turn frames how a study will be conducted (Cibangu 2010). Quantitative research adopts a positivist epistemological position which presumes that phenomenon can be measured according to the practices of a natural science model, whereas the epistemological position of qualitative research is interpretivism, which emphasises the way in which individuals interpret their social world (Bryman 2016a). The ontological orientation for quantitative research arises from a view that social reality is objective. This is compared with a view of reality that is named constructionist in qualitative research, which supports the idea that reality is constructed or made sense of by an individual (Barab et al 2007). In this way, Bryman (2016a p.26) states that interpretivism uses a "different logic of research procedure, one that reflects the distinctiveness of humans against the natural order". In this study, it is certainly the distinctiveness of both the human experience in conjunction with understanding advances in surgery that lends itself to a method of qualitative enquiry in order to capture those unique aspects of human understanding and associated meaning. Typically, sample selection, data collection and data analysis tend to differ depending on which research paradigm is selected. Bryman (2016b) points out in his critique of each method, that qualitative research can be more subjective, less generalisable and harder to replicate mainly due to smaller sample sizes and the disparity between participant response, whereas quantitative methods produce more valid, generalisable results due to larger sample sizes and more controlled variables. However, it is worth noting that it is harder to attach personal meaning to quantitative research or answer questions of a moral or ethical nature (Malterud 2001). Considering the above it can be seen that a qualitative research paradigm is best placed to explore the patient experiences of those being considered for surgical resection of liver metastases.

5.5.2 Hermeneutic phenomenology

The use of qualitative research in health and social science arose from a growing disenchantment with the limits of quantitative research in the 1980's (Osborne 1994). During this time, there was a pulling away from empirical methods as used in positivism and a search

for methodologies that would be responsive to the realm of human knowledge. Laverty (2003) refers to some popular methodologies as phenomenology, hermeneutic phenomenology, ethnography and grounded theory that grew out of an appeal against positivism. This next section will focus on phenomenology and hermeneutic phenomenology in order to show why this study will adopt a hermeneutic phenomenological inquiry based on the work of Gadamer. It will begin by setting the historical context and relevance of the distinctiveness of phenomenology and hermeneutic phenomenology, in which the background of Gadamer's work is set.

A key methodology of interpretivism is phenomenology. Phenomenology has its roots in 20th Century Eastern philosophy (Starks & Trinidad 2007). As indicated above, Edmund Husserl (1859-1938) is often referred to as the father of phenomenology (van Manen 1997). A mathematician by profession, Husserl developed his thinking on understanding conscious experience following his dissatisfaction with the natural science model adopted in positivism which he saw as inflexible to individual experiences (McConnell-Henry et al 2009). Husserl criticised psychology in its methodology as humans were living subjects and did not have automatic, controlled reactions. He felt that important variables were omitted in psychology that only served to create artificial situations. This denotes somewhat of a drawing away from Cartesian dualism as proposed by Descartes who saw a division between the state of mind and the state of body (Laverty 2003). Phenomenology is essentially the study of lived human experience in the world (van Manen 1997) and as such is well suited to exploring people's life experiences (Parahoo 2006). Starks and Trinidad (2007) write that analysts of phenomenology look to capture what are the meanings and common features of human experience. Indeed Parahoo (2006) believes that phenomenology is well placed to explore patients' experiences of illness. As Simpson & Whyte (2006) outline, phenomenology is linked to the ontological question 'What is being?'. This sits well with this study which focuses on patient experiences during consideration of surgical resection of liver metastases, a crucial period where there is tension between the hope of life that the surgery might offer against the reality that may present itself if surgery is not possible. A Finnish study by Saeteren, et al (2011) certainly described a co-tension between the possibility of life or death among 15 patients with advanced cancer, as 'latching onto life', even though there was no more treatment that could be offered. It's therefore important to explore meaning in a situation, where despite the presence of metastatic disease, the hope of a cure is offered through surgery.

A key feature of Husserlian phenomenology is the concept of 'reduction' or 'bracketing'. Husserl believed that one's own judgements about the phenomena to be studied required to be suspended in order to accurately see the phenomena more clearly. Giorgi (2007) writes that Heidegger was eager to find a method that led to gaining secure knowledge and incorporating reduction allowed him to do this, where careful emphasis was placed on description. Perhaps it is not surprising that with Husserl's background in mathematics and logistics he placed so much emphasis on description. The method of bracketing was later applied to the social sciences by Alfred Schutz (1899-1959) who advocated the researcher to block out their own preconceptions in order to gain as pure as form as possible of the participants' experience (Bryman 2016a). In Laverty's paper (2003) she asks the question how does one actually go about this process? Laverty draws on descriptions by Klein & Westcott and Polkinghorne that essentially use careful description of the phenomena studied to reduce personal presuppositions. However, the reality may be that not even the researcher can escape their own social constructions.

This leads onto a consideration of the place of hermeneutical phenomenology in qualitative research. Hermeneutics is the theory of interpretation (Smith et al 2009). Schleiermacher, considered as one of the early fathers of hermeneutics, defined hermeneutics as "the art of understanding the discourse of another person correctly" (Schleiermacher as cited in Bowie 1998, p.xx). Hermeneutical phenomenology can best be attributed to the German philosopher Martin Heidegger (1889-1976). Heidegger moved from theology into philosophy and taught at Freiberg University, eventually taking over Husserl's professorship (Laverty 2003). However, as time went on, Heidegger disassociated himself with Husserlian thinking which had focused on studying phenomena through careful description involving reduction and he began to develop phenomenology from an ontological position (Giorgi 2007). Heidegger became concerned with the question of being and to some extent this may not be surprising, given his roots in theology. Heidegger referred to the German word 'dasein', meaning being or existence, and set out the importance of this concept in his work 'Being and Time' (1962) where he pursues the question of being. In contrast to Husserl, Heidegger believed that the state of consciousness is inseparable from the history of our lived experience (Polkinghorne 1983) and gave voice to the concept that pre-understanding of the world is not something that we can set aside. While Heidegger understood the stance that Husserl took on concept reduction, he did not embrace it and pulled further away from a Cartesian dualism than Husserl ever did. Heidegger believed that all interactions on a human

scale require interpretation and we do this by relying on our backgrounds, or what Heidegger names 'historicality' (Lawn 2006). As understanding was essentially wrapped up in being, much priority was therefore given to interpretation rather than purely description. Rather than seek to set aside our pre-understandings of phenomenon to be studied, Heidegger sought to become as aware of them as possible and account for them. Taylor (2001) writes that in this way, hermeneutical phenomenology can acknowledge the researcher's involvement in the making of and presentation of the data and in acknowledging any pre-existing judgements about the patient group to be researched.

As a philosopher, immersed frequently in written texts, Heidegger had devised what he named a 'hermeneutic circle' in order to understand and attribute meaning in a text. Individual parts of text or the whole text could not be understood without reference to other parts of the text and in this way the search for meaning became circular (Polkinghorne 1983). In the same way that Heidegger's concept of the hermeneutic circle (1962) expressed the process of retrieving meaning from a text with reference to its cultural and historical context, hermeneutic phenomenology could be used to find meaning among lived experiences (Annells 1996). Much of this experience is hidden or often the taken for granted and requires to be exposed. Therefore, Heidegger believed that accessing texts could bring to the fore meaning and make the implicit more explicit. Laverty (2003) includes written, verbal, visual arts or music as examples of texts. The study of texts has been especially relevant to this study as recordings of interviews and a focus group have yielded transcripts which can be analysed for not only the obvious but for the hidden as well, for example cultural, environmental constraints.

5.5.3 Introducing Gadamer

Hans-Georg Gadamer (1900-2002) is, arguably, responsible for the extension of hermeneutic phenomenological thinking. Gadamer was taught under both Husserl at Freiburg and Heidegger at Freiburg and Marburg University (Laverty 2003). While Heidegger focused on the question of being, Gadamer extended this to ask, how was understanding possible? In this way his work has a practical extension of Heidegger's in application to research (Laverty 2003). He was particularly concerned with understanding when life occurs "over and above our wanting and doing" (Gadamer 2013, p.xxvi).Undoubtedly when placed in the context of a diagnosis of metastatic cancer, these words sound a poignancy for those experiencing life

in the midst of a diagnosis that occurs 'over and above... wanting and doing'.Gadamer agrees with Heidegger in the importance of language as the key to understanding, stating that,

"Language is the universal medium in which understanding occurs. Understanding comes through interpreting". (Gadamer 2013, p.407)

and

"Understanding is always more than merely re-creating someone else's meaning. Questioning opens up possibilities of meaning and thus what is meaningful passes into one's own thinking on the subject…" (Gadamer 2013, p.388).

In this way further reference is made to the hermeneutic circle, whereby language is to be understood as part of the whole. There is a constant movement which runs back and forth until all of the text is understood (Polkinghorne 1983). Flowing on from this is the idea that we cannot bracket off our consciousness when we approach text or others experience but we come to interpret it in what Gadamer calls a 'fusion of horizons' (Gadamer 2013). He describes this horizon as a vision which includes everything seen from a vantage point. The ability to question oneself as well as interpret the data is a constant process which gives new horizons (Laverty 2003) or as Gadamer suggests the fusion of the text's horizon with that of the interpreter. To some extent Gadamer acknowledges that a level of prejudice (i.e. foreknowledge of the phenomenon to be studied) is vital in achieving meaning (Annells 1996, Laverty 2003). Gadamer was not without his critics, with notably Habermas criticising Gadamer's reliance on tradition without apparent question and Derrida taking the view that Gadamer's understanding of the person meant the individual was to be seen as correct in their understanding (Lawn 2006). Many of these differences were reconciled through discussion but Gadamer's hermeneutics are particularly suited to this study. Indeed, in the consideration of resection of liver metastases I, myself as researcher had a fore-knowledge of the clinical system and pathway and therefore an awareness of some of the 'traditions' that it may hold. I had also conducted the interviews and been present at the focus group and as such has had exposure to the process of interpretation that starts at data collection. Rather than abandon this level of foreknowledge, hermeneutical phenomenology as proposed by Gadamer, would suggest that this level of knowledge is essential in the overall interpretation and search for shared meaning. Further to that, a starting point of belief what the patient shared was essential to consider change. As this study has a focus on service development and improvement, Gadamer's hermeneutic philosophy will become heavily

relied upon in order to utilise the data and make changes to the pathway in the context of a known hospital environment.

5.5.4 Contribution of van Manen to hermeneutic philosophy

At this point it is necessary to refer to the impact of the Canadian phenomenologist Max van Manen (1942 – present) on hermeneutic philosophy. Van Manen's work stemmed from his dissatisfaction with pedagogical approaches to education in the Netherlands which contrasted to a more systems analysis approach of North American education. Van Manen's work has gained contemporary popularity not only among educationalists but also among nurses and health care practitioners (Dowling 2007, Earle 2010). Indeed, Van Manen's publication of *Phenomenology of practice: Meaning-Giving Methods in Phenomenological Research and Writing* (2014) draws on the meaning and practice of phenomenology in professional contexts of healthcare and psychology as well as pedagogy and education. His development of four fundamental existentials, (or lifeworld themes) named, Spatiality, Corporeality, Temporality and Relationality, (van Manen 1997) have been widely used in providing guidance for researchers approaching phenomenological writing (Dowling 2007). While of this has an attraction, there were several reasons why I wanted to inform the study by Gadamerian philosophy rather than van Manen's. Firstly, I was attracted to Gadamer's teaching on phenomenology as being a product of the early father's of phenomenological debate and secondly, he was the first to acknowledge the fusion of horizons. This was concept was particularly important to me as I not only wanted to reflect my place as researcher in coming to an interpretation with the participants but I also wanted to reflect 2 further fusion of horizons, that of my role as insider-outsider researcher and the fusion of the input of the health professionals with the participants.

5.6 Research aims

The following points set out the aims of this phenomenological inquiry concerned with patient experience of the pathway to CRLM resection;

- To investigate how patients experience the pathway to liver resection
- To examine how health care professionals view the pathway to liver resection for patients

●To use the experiences of both patients and health care professionals to plan and implement a service improvement to the pathway with the addition of supportive nursing intervention.

●To explore whether additional nursing interventions during this pathway improve the experiences of patients being considered for surgical resection of liver metastases following service change.

5.7 Research Method

In order to investigate these aims, this phenomenological inquiry has been designed in two phases. Phase 1 involved patient interviews (semi-structured) with a patient sample group in order to assess the experiences of patients who had been considered for CRLM resection. This phase also included a focus group with a group of health care professionals involved in the pathway to liver resection to assess their experience, personal challenges and perceptions of the current pathway.

An interim period was built into the study to evaluate the findings from the patient interviews and the health care professional focus group. The researcher and nursing team, together with the support of the study steering group utilised these findings to consider what support changes could occur in the pathway and what additional nursing interventions could be offered to support patients through this demanding pathway. The model of nursing intervention was dependent and reflected the findings from Phase 1. The second phase also involved interviewing a further patient sample group who were considered for liver resection following implementation of the service change. A further focus group with the health care professionals was also conducted to ascertain change.

Figure 5.1 overleaf, shows the study schedule. I set out to maintain the sequence of events as and timing as indicated in the study schedule to honour requirements of the study funding. During this time, I also met the requirements of six-monthly study progress reports to the local Health Foundation and ensured feedback of progress to the study steering group. I was also able to undertake relevant courses and workshops to equip me for the role of researcher.

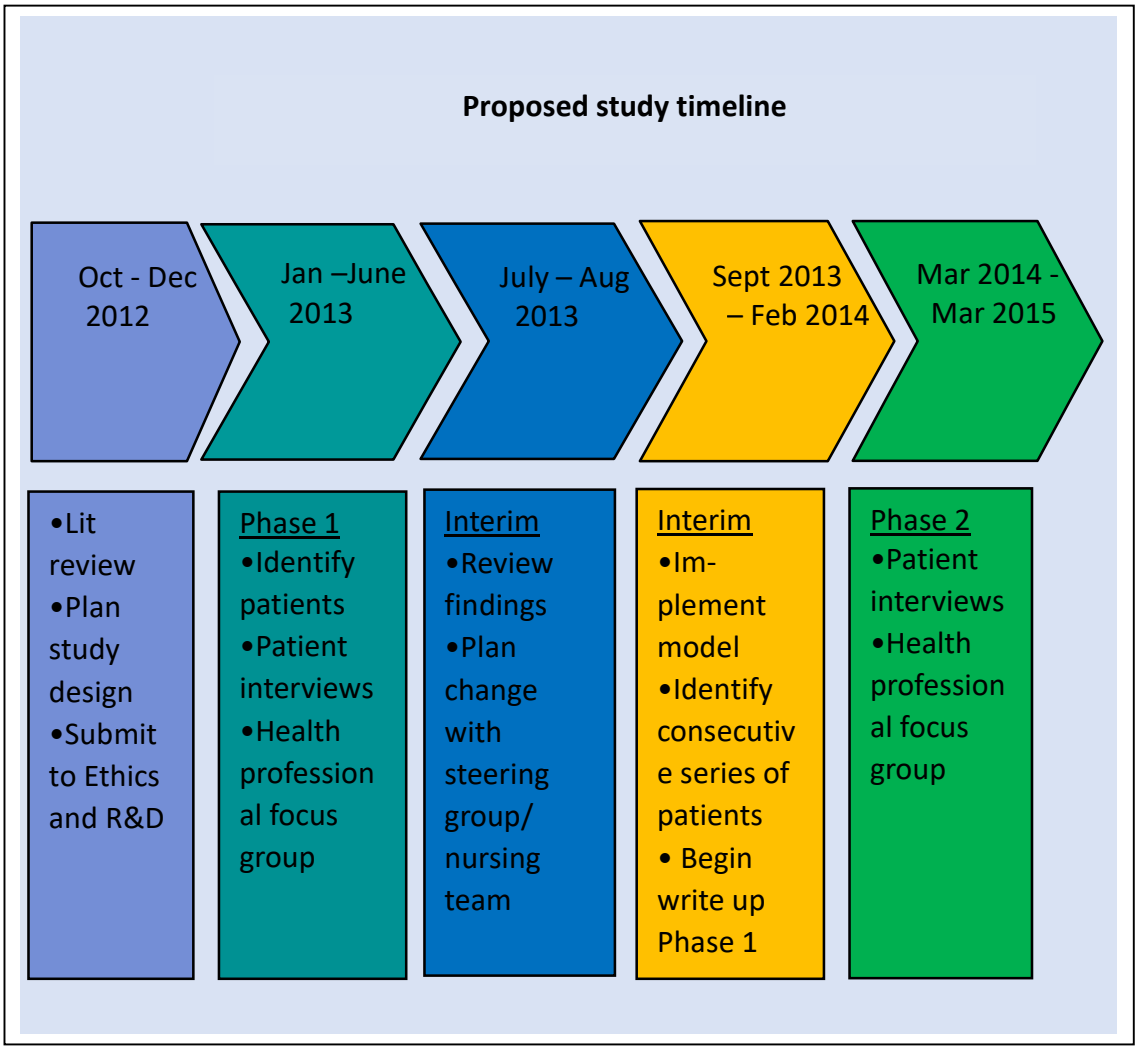


Figure 5.1: Timeline of study events

5.7.1 Samples and setting

Patients who were considered for liver resection during the time period of 2011-2012 were recruited to the study using a purposeful maximum variation method. A purposeful sample method is the most common sampling method used in phenomenological methodology in qualitative research (Simpson & Whyte 2006). It is well matched to the proposed study as it is assumed that people who have experience of the hepatic resection pathway are best placed to improve the knowledge in this area. A random sampling method would therefore serve no purpose in this study. In qualitative research, smaller samples are acceptable as they enable in-depth study of an experience and thus allow for a richness of data about an individual experience (Bryman 2016b, Worster & Holmes 2009). The study was also conducted within a restricted timeframe so a smaller sample number allows the researcher realistic parameters for data collection and analysis.

As qualitative research is 'data dense', smaller sample sizes can be considered when compared to those required for quantitative studies where attention may be given to calculating prevalence of a phenomenon or statistical trends. A previous qualitative study in this area, conducted in America, (McCahill & Hamel- Bissell 2009) had twelve patients and smaller sample sizes of eight to twelve participants are deemed adequate for interview work of an exploratory nature (Bryman 2016b). Sample size was achieved when the point of theoretical saturation was reached, that is, when there was confidence that recurrent themes are expressed and no new thematic data was emerging.

Currently there are no prospective database systems in place to readily identify patients who have been considered for resection of liver metastases from a colorectal cancer primary. However, based on in house figures from the hepatobiliary unit in 2012 there were over thirty patients who had a liver resection and a further eight patients who were considered for a liver resection but did not proceed, for a number of reasons, although some of these also included patients who developed additional metastatic presentation, e.g. lung. Further discussion with members of the multidisciplinary colorectal cancer team suggested that patient recruitment should be relatively easily secured.

According to the maximum variation principle, often adopted in purposeful sampling, the intention of the study was to recruit patients with a range of experiences, e.g. those who had synchronous liver metastases and metachronous liver metastases, those who have had clear operability and borderline operability. This will therefore include patients who have been successful in proceeding to a liver operation and those who have not, for a number of reasons (e.g. disease recurrence, failure to respond to chemotherapy, co-morbid complications). Including patients who did not have liver resection is seen as a measure of improving validity, as it may be that there was a tendency for those achieving liver resection to reflect back on the pathway more favourably considering their more favourable outcome. The diverse inclusion among the study sample allowed for the patient population to be reflected across its breadth of population. This, importantly added credibility to the study sample and research as a whole. It is important to stress that the focus is on the pathway as a whole rather than on the outcome of being considered for surgical resection of CRLM. The study inclusion/exclusion criteria for patents are listed in Table 5.1.

An important consideration when agreeing eligibility criteria was a firm agreement to those with liver only metastases. As noted in Chapter Three, it is not only with liver metastases

where advancements in metastatic treatment have been seen. Initial discussions with clinicians involved in the treatment of those with CRLM expressed such concerns and that it would be good to include those who had for example liver and lung metastases.

Inclusion criteria	Exclusion criteria
- All patients with liver only metastases of colorectal origin being considered for surgical resection of liver metastases. - Patients treated within the boundaries of NHS Lothian. - Patients who are able to provide informed consent to allow for participation in the study. - All patients over age 18.	- Patients with other known metastases originating from a bowel primary, e.g. lung, peritoneal metastases. - Patients with known cognitive impairment which would make it difficult to elicit their experience through an interview method. - Patients with known significant mental health diagnosis which would make it difficult to elicit their experience through an interview method.

Table 5.1: Study eligibility

Notably this would have increased the potential for patient recruitment. However, although these thoughts were acknowledged it was decided to focus on those with liver only metastases as the introduction of the surgical management of a non-liver metastases can make for a more complex and very different pathway. In addition, as outlined in Chapter three, liver only metastases are more frequently occurring and historically the case for surgical treatment is more developed. These sentiments were also echoed by the steering group.

The study was confined to those in NHS Lothian. Patient interviews took place on the premises of either two local teaching hospitals or in the patient's own home. Locations within the two teaching hospitals were used for the health professional focus groups in both Phases.

5.7.2 Phase 1

Nineteen patients were eligible from information provided from an in-house hepatobiliary database of patients considered for liver resection in 2011 and 2012. A good response to invitation by letter was received, with 16 patient interviews taking place between March-June 2013. Three patients declined, two expressing that they would rather 'move on' from this period and one as he was taking the opportunity to travel for an extended period out with the interview period. Twelve of the sixteen patients who consented, had undergone liver resection and four became ineligible for resection. For two of these patients this was

due to disease progression and for the remainder two due to associated co-morbidities. Table. 5.2 overleaf displays the characteristics of the study sample for Phase 1.

The focus group was conducted in May 2013 at a local Maggie's Centre, and was attended by four health professionals. Two could not attend due to emergency liver transplant but one (Consultant Hepatobiliary surgeon) was later interviewed by the focus group facilitator on a separate occasion. This demonstrates the reality of conducting research within a reactive clinical setting. Table 5.3 overleaf displays the make-up of the Phase 1 focus group.

5.7.3 Interim period

An eight month interim period (July 2013 – February 2014) allowed for data analysis from Phase 1 and implementation of a new model of support for patients undergoing CRLM. This time also allowed for consideration of suitable approaches in response to the findings and development and implementation of one model of support for patients. This interim period is detailed in Chapter 7 and focuses on the background and rationale for the development of a systematic nurse-led telephone support model, development of a patient information series regarding colorectal liver resection and a formation of a patient buddy support service.

Following the interim period, it then became possible to begin patient recruitment to evaluate the experience of future patients who were being considered for CRLM and to ascertain the value of the implementation of the support model. Using purposive sampling, potential participants were identified prospectively from the colorectal multi-disciplinary meeting from January 2014 – December 2016. The majority of interviews were conducted by December 2015 but due to the often elongated nature of the pathway, it took until December 2016 to recruit patients who did not proceed to liver resection. This is an important consideration because the previous patients in Phase 1 had been recruited retrospectively. In this phase, patients were required to be identified prospectively but could not be approached until after liver resection was completed or a definite decision not to proceed to liver resection had been confirmed with the patient and documented. Interviews continued until data saturation which was easily reached for those had proceeded to liver resection.

Participant Name	Gender	Age at diagnosis	Presentation of CRLM	Treatment sequence	Resection, Yes/No
Helen	Female	62	Metachronous (during follow-up)	Primary surgery→ adjuvant chemo→ liver resection→ subsequent 2 liver resections	Yes x3
Chris*	Male	53	Synchronous	Primary bowel surgery→ chemo →liver resection	Yes
Andrew*	Male	66	Synchronous	Primary bowel surgery→ chemo→liver resection	Yes
Craig	Male	55	Synchronous	Primary bowel surgery→ chemo→liver resection	Yes
Alex	Male	70	Metachronous (during follow-up)	Primary bowel surgery→ adjuvant chemo→liver resection	Yes
Paul	Male	70	Synchronous	Primary bowel surgery + defunctioning stoma	No
Scott	Male	63	Metachronous (during follow-up)	Short course radiotherapy→primary bowel surgery→ adjuvant chemo→liver resection	Yes
Amy	Female	65	Synchronous	Synchronous primary and liver resection→chemo	Yes
Laura	Female	76	Synchronous	Primary bowel surgery→ chemo→liver resection	Yes
Steven	Male	72	Synchronous	Short course radiotherapy→Primary surgery	No
Richard	Male	77	Synchronous	Primary bowel surgery→ chemo→liver resection	Yes
Tom	Male	57	Synchronous	Primary surgery→chemo	No
Jennifer*	Female	74	Synchronous	Synchronous primary and liver resection	Yes
Robert	Male	63	Synchronous	Primary bowel surgery→ chemo→liver resection	Yes
Lynn	Female	62	Synchronous	Primary bowel surgery→ chemo→liver resection	Yes
Julia	Female	60	Synchronous	Primary surgery→chemo	No

Table 5.2: Study Characteristics of Phase 1 participant sample

*Patients requiring Portal vein embolisation (PVE) prior to liver resection

Health professionals present at focus group Phase 1
Focus group facilitator
Oncologist 1
Oncologist 2
Colorectal surgeon
Colorectal nurse specialist
Researcher (myself) as observer

Table 5.3: Health professional make-up of Phase 1 focus group

5.7.4 Phase 2

Once again, a good response to invitation by letter was received with thirteen patient interviews taking place between July 2014 - June 2015. Five out of the 18 patients approached, declined, expressing in a similar way to those in Phase 1, that they would rather 'move on' from this period and concentrate on their recovery and follow-up. During this period, July 2014 – June 2015 there were just under fifty patients eligible for liver resection but it took longer to follow through and find patients who became ineligible for liver resection. For Phase 2 of the study, twelve participants had undergone liver resection and four became ineligible for resection. All four of these patients could not proceed due to disease progression where it was apparent that interim imaging had upstaged their initial potentially resectable disease. Table. 5.4 overleaf displays the characteristics of the study sample for Phase 2.

The focus group was conducted in May 2014 at a large teaching hospital for the convenience of those representing the hepatobiliary service. It was attended by six health professionals. Table 5.5 displays the make-up of the Phase 2 focus group.

5.8 Practical considerations

A number of practical considerations were important to the recruitment process and ensure patient throughout the process. These are outlined in turn.

5.8.1 Access to participants

Appropriateness of potential patients for the study was checked with a respective consultant before an invitation letter and information letter from a consultant of the direct care team was sent (see Appendix II – V for examples of patient study documentation). Patients were invited to respond by telephoning the research office or returning a response slip in a stamped addressed envelope. The researcher and an independent study adviser were introduced in this documentation. Participants were made aware that, should they participate, their GP would be informed (see Appendix VI). Potential participants in the health professional group were known to the researcher and members of the multidisciplinary team were invited by letter from the researcher with an attached information letter (see Appendix VII – VIII for examples of health professional documentation). Documentation was adjusted according to Phase 1 or Phase 2 for patients and health professionals.

Participant	Gender	Age at diagnosis	Presentation of CRLM	Treatment sequence	Resection, Yes/No
Lisa	Female	49	Synchronous	Primary bowel resection→ chemo→liver resection	Yes
Ruth	Female	60	Synchronous	Chemo with cetuximab→ liver resection→primary bowel resection	Yes
Chloe *	Female	34	Metachronous	Primary bowel resection with temporary stoma→Stoma reversal→adjuvant chemo→liver resection	Yes
Archie	Male	77	Synchronous	Primary bowel resection→liver resection	Yes
Charles	Male	68	Synchronous	Primary bowel resection→chemo→liver resection	Yes
Susan	Female	61	Metachronous	Primary bowel resection→adjuvant chemo→liver resection→chemo	Yes
Hamish	Male	68	Metachronous	Primary bowel resection→adjuvant chemo→liver resection	Yes
Karen	Female	59	Metachronous	Primary bowel resection→further bowel resection for adhesions→chemo→liver resection	Yes
Judith	Female	72	Metachronous	Primary bowel resection→liver resection	Yes
Carol	Female	73	Metachronous	Primary bowel resection→liver resection	Yes
Mark	Male	51	Synchronous	Defunctioning stoma→downstaging radiation to rectal primary→primary bowel resection, pelvic extenteration + urostomy→liver resection	Yes
Diane	Female	73	Synchronous	Synchronous bowel resection with liver resection	Yes
Kenneth	Male	60	Synchronous	Bowel resection→chemo	No
Daniel	Male	52	Synchronous	Bowel resection→chemo	No
Ann	Female	67	Synchronous	Bowel resection→chemo + cetuximab	No
Greg	Male	54	Metachronous	Bowel resection→adjuvant chemo→palliative chemo	No

Table 5.4 :Study Characteristics of Phase 2 participant sample

*Patients requiring Portal vein embolisation (PVE) prior to liver resection

Health professionals present at focus group Phase 2
Focus group facilitator
Oncologist 1
Oncologist 2
Colorectal surgeon
Colorectal nurse specialist 1
Colorectal nurse specialist 2
Hepatobiliary surgeon
Researcher (myself) as observer

Table 5.5: Health professional make-up of Phase 2 focus group

5.8.2 Timing and presentation

Checking a patient's eligibility with a respective consultant ensures that recruitment to patient interviews are well managed. This may reduce patient distress particularly in cases where patients are still receiving chemotherapy following liver resection or receiving ongoing treatment for complications encountered as part of overall treatment. Potential participants for the patient interviews were given at least one week to consider the invitation letter before the researcher made a follow-up phone call to answer any queries and ascertain interest. In the majority of cases this follow-up phone call was not required. The researcher ensured that they were clearly introduced, taking the time to check receipt of invitation letter and that the potential patient had the time to talk. Caution was exercised to ensure that no coercive language was adopted during the call. For those wishing to proceed , an agreed date, a time and location of the patient's choice was made.

Potential health care professionals were given one week to respond to the invitation letter. A lack of response was followed up by an email to ascertain willingness and availability. Once participants were confirmed, care was taken to set a convenient date, time and location for the focus group. Patients were invited to participate in one interview lasting approximately one hour and similarly the health care time commitment was approximately one hour. A different set of patients and health care professionals were then asked to repeat interviews and a focus group respectively after a planned intervention in the interim period.

5.8.3 Development of interview/focus group schedule

Themes for the interview and focus group were developed according to literature outlined earlier and on discussion with colleagues in multidisciplinary team. An example interview schedule can be viewed in Appendix IX for those patients participating in semi-structured

interviews. Questions were adapted at the time of the interview according to (a) patient's disease presentation and (b) response given. This ensured that the interview was participant led. An independent facilitator adapted the themes and questions used for the patient interviews to the health professional focus group in order to develop a discussion schedule.

5.8.4 Data collection procedure

In both ***Phase 1*** and ***Phase 2***, semi-structured interviews were used with patients and one focus group with Health Care Professionals. Both interviews and the focus group were audio-recorded for transcription and analysis. Patient interviews lasted for approximately one hour and included a number of open questions. Prompts were used to aid the participant in discussion and check understanding but care was taken to avoid leading questions or influencing participants' responses.

Health care professionals involved in the colorectal cancer pathway were invited to take part in a focus group lasting one hour. An independent facilitator was used to facilitate group discussion. This was of value as the researcher was considered to be too closely connected to the health professional participants and allowed for some distance. Open ended questions were adopted and prompts were used to check understanding and elicit further discussion. Questions with the same themes used for patient interviews were used with the focus group, but were angled towards their role as health care professionals. Written consent was obtained before commencing participant interviews and the focus group.

5.8.5 Rigour, credibility and trustworthiness

There is an ethical responsibility to conduct rigourous research and all research should be underpinned by principles of rigour, credibility and trustworthiness. These principles apply to quantitative research but the means by which they are achieved in qualitative research will differ according to their ontological base (Leung 2015). Rigour should be evident throughout a study from design to data collection, analysis and dissemination. Maintaining rigour is a way of preventing harm to participants and to ensure the credibility and trustworthiness of findings for further application. Criteria for determining trustworthiness were introduced by Guba & Lincoln in the 1980s opting to replace commonly used terminology for achieving rigour, such as reliability, validity and generalisability with dependency, credibility and transferability (Morse 2015). In this study, rigour was ensured through my integrity as a researcher and the use of reflexive practice (Avis 2002) as more

fully expanded in section 5.10.4. Regular discussion with supervisors on particular aspects of study design, ethical considerations, sample population, analysis and dissemination of results were key to maintaining both rigour and credibility.

Credibility was ensured by several means. My sustained period of involvement in the study helped to confirm that I had a good knowledge of the area, alongside my inside knowledge of the existing area. Peer debriefing with members of the steering group, immediate team members and member checking of transcripts also helped to limit bias and reduce omissions (Lapan et al 2012). This is further detailed in Sections, 7.2.1, 7.2.2. and 9.10. Keeping a researcher journal to document my understanding of the research journey was also useful to self check my own thoughts guiding the analysis. Finally, using the fusion of horizons as outlined at the outset in Chapter 1, Section 1.2, reflected a blending of viewpoints, (patients, health professionals and my own as insider-outsider reseacher). This can be considered akin to triangulation, a method used to enhance the trustworthiness of qualitative research, by utilising different sources of data on the same topic to compare and contrast differences and similarities (Schensul 2012). This adds a strength to the methodology in that the topic of CRLM under scrutiny is supported by the gathering of information from different groups. This in turn supports and validates each source, increasing data trustworthiness.

5.9 Chosen qualitative method: the medium of interview

It would appear that interviews play a crucial part in our society in understanding the world we live in. Interviews appear to be everywhere. They are never far from the 'flick of a remote' or remnants overheard in a more casual social setting. The idea of the 'interview society', a term coined by David Silverman (2017) is one with which we can readily identify, yet the apparent infiltration of the interview could give rise to the idea that conducting an interview requires nothing more than everyday conversational skill (Holstein & Gubruim 2004, Rubin & Rubin 2005, Atkinson & Silverman 2007). When placed in the context of research, the interview is seen as an art or craft, something requiring a unique skill set and an understanding of the process and associated investment and risk to both the researcher and participant (Kvale & Brinkman 2009, Roulston 2011). Loftland and Loftland (1995) argue that when undertaking research interviewing, the researcher should expect to come into contact with some raw human emotion. This may especially be the case when conducting interviews involving a sensitive or emotive issue as is the case in this study subject. The medium of

interview became an important way to 'be with' the participant in sharing their horizon of interpretation, and in understanding heard language as vital to that understanding and future interpretation. This became important in reflecting a key component of Gadamerian thinking of interpretation. For this reason, the next sections, outline some considerations in undertaking interviews.

5.9.1 The context of the research interview: an emotionally sensitive nature

While the advances in the treatment of liver metastases are hugely exciting, (as detailed in Chapter 2), observations in the care setting would suggest that the pathway to liver resection is extremely demanding for patients, with the pathway taking several months for surgical workup depending on tumour presentation, pre-operative imaging and possible requirement for chemotherapy. The day to day reality, is that discussions are inevitably of an emotionally sensitive nature. Defining what constitutes an emotionally sensitive issue among participants is not straightforward. There appears almost to be a taken for granted understanding of what is meant by emotional sensitivity when reading research literature. While this may be more obvious from situations presented in papers such as Gadd's (2004) work in violence in intimate relationships or Goodrum & Key's (2007) studies in bereavement from murder and abortion, defining a subject as emotionally sensitive may not necessarily mean that it is perceived as such by a participant. The Oxford English Dictionary defines emotion as 'a strong feeling deriving from one's circumstances, mood or relationship with others' (Oxford University Press, 2018, para.1). In this study, I was keen not to assume that the interviewees would necessarily encounter the interviews as emotionally sensitive but equally I wanted to be attuned to the possibility that the interviews held that potential of confronting the participants with raw emotion. This may be especially the case when participants reflect back on events either pertinent to their treatment, or to events at that time, or to current events coinciding with the time of recalling the information.

Before discussing the skills required during the interview process, this section will address issues considered as essential pre-requisites to facilitate the interview process. These pre-requisites are important for any type of research interviewing, but in the context of interviewing participants where emotionally sensitive issues could become apparent, robust preparation and adequate thought must prove beneficial to both the researcher and potential participants. This is a sentiment echoed by many researchers (Mason 2002, Hubbard et al 2001, King & Horrocks 2010). The overall process of preparation can set the

tone for the actual interview by providing safeguards to both the researcher and participant in reducing the risk of potential harm and enabling a more critical process of researcher inquiry which may in turn facilitate the generation of richer interview data.

5.9.2 Establishing the interview approach and schedule

When studying a particular participant group the researcher needs to identify the most appropriate research design and methodology pertinent to the group and associated research question (Rubin & Rubin 2005, Bryman 2016b). Bearing this context in mind, the use of the research interview is a useful qualitative tool, ideally placed to elicit knowledge and understanding in an area where little is known (Mason 2002, Rubin & Rubin 2005). A qualitative research design using phenomenological method was used in this study as it is suited to explore the subjective world of human experience rather than quantitative research (King & Horrocks 2010). Utilising a quantitative approach and tools would only fail to yield meaningful data and would not reflect an ontological position which considers people's knowledge and experiences are meaningful properties in the social world (Mason 2002).

Before approaching their participant group, the researcher should consider the issues faced by the potential participants. This may arise from relevant literature or *a priori* knowledge from previous contact with the participants or perhaps from related research. This consideration may then form the basis of an interview schedule which may be used to guide the interview or act as an aide memoire to the researcher. How structured or unstructured the interview should be is something the researcher will need to decide upon as suited to the participant group and data. In their paper, Corbin & Morse (2003) helpfully outline, three different modes of interviewing in a table (structured, semi-structured and close-ended questioning) along with their associated control over the interview from the researcher and participant's perspective. Corbin & Morse (2003) suggest, that when dealing with sensitive issues, the use of the unstructured interview can give more control to the participant and this can allow the interview to be set at the pace of the participant therefore putting them more at ease. However, Corbin & Morse are quick to point out that this unstructured approach has its own risk. It clearly shifts the power dynamic and conversation to the participant, which carries the risk that the researcher may not get the data relating to certain phenomenon they wish to explore.

A semi-structured interview was used with the focus on a collaborative or facilitative interviewer-participant relationship. This helps to balance the perceived power dynamic between researcher and participant. Sinding & Aronson (2003) report that unequal power dynamics can often be evident particularly where care has failed in healthcare. In interviews that have already been conducted by the researcher in Phase 1 of the study, the researcher found that the majority of participants led the conversation as they relaxed into the environment and the researcher did not have to diligently adhere to the schedule as if in some robotic style of questioning. However, familiarisation with the interview schedule did mean that in rare times when the conversation 'dried' then the researcher always had a direction in which to guide further exploration. On reflection, a structured interview schedule would have been too inflexible and may have hidden some of the emotional aspect that needed to be uncovered.

5.10 Adopting ethical safeguards

Hubbard et al (2001) are quick to point out that ethical issues are certain to be present when researchers look at emotionally sensitive topics. Traditionally Fontana & Frey (2005) have reported that ethical considerations revolve around three key concerns; informed consent, right to privacy and protection from harm. Knowing or having access to the participant pool is central in achieving consent (Schulman-Green et al, 2009). Care should be taken to avoid participant pressure and to allow adequate time to weigh up involvement. In the case of the liver metastases study, the ethics committee did acknowledge that participants were likely to experience emotional vulnerability and they requested that the participant invitation letter was sent from a named oncologist in order that the study was directly connected to their direct health care team (see Appendix II - IV). This allowed additional support in the case of emotional challenges arising as a result of their care that had been triggered by the interviews. Oncology based psychological support was also built into the study support structure should patients wish to take this up. Both these measures allowed clear boundaries between the researcher and interviewer.

5.10.1 Consent

For those participants in the patient group, informed consent was sought by signature to ensure agreement. The informed consent document was sent out in the original information pack and some participants chose to return it signed to the research office while for others,

consent was taken prior to the research interview. The interviews took place within 1-3 weeks of ascertaining that the participant was happy to proceed. The consent document was taken to the interview if it had been signed earlier and discussed again as a further way of checking that the participant was happy to proceed. It was always co-signed by myself as researcher before the interview began. This allowed for time to ascertain understanding of the participant's involvement before the interview commenced. Consenting to only one interview prior the interview began, made it unlikely that a participant would not proceed. Informed consent was also taken by the researcher prior to the focus group for those in the health professional group. Participants in this group also received a written information sheet about the study beforehand.

5.10.2 Data storage and confidentiality

Local 'in-house' hospital databases and medical records were reviewed to screen identifiable personal information of patients. Electronic transfer of data from patient databases was encrypted for transfer and stored only on a hospital secure drive. Information from the databases was extracted by hospital staff who already had authorised access as part of their routine workload. Medical records were reviewed by myself in the capacity of both researcher and, as part of the existing clinical care team. Personal contact details of participants and consent records were treated sensitively and kept in a locked drawer of a filing cabinet along with any identifiable patient files and audio files. All publication of direct quotations will be anonymised and no data has been published or presented that would allow individuals to be identified. Coded transcripts were stored on a NHS computer with existing safety access controls in place. No identifiable data was shared with the transcriber. As a member of the direct healthcare team, the researcher adheres to the Data Protection Act and NHS Code of Confidentiality and has ensured that the study was conducted in adherence to these policies.

An independent risk assessment was also performed by the local Clinical Trials Monitor and by the local Quality Assurance Group with the outcome that no regular monitoring of patient safety was required throughout the study and that no audit required to take place before, during or after the study.

5.10.3 Minimising the possibility of harm

Even though the nature of the interviews were likely to be emotionally sensitive, it was anticipated that no prolonged emotional harm would occur to the participants. Although everything possible was in place to minimise distress, it was recognised that a patient interview may trigger emotional upset when discussing issues relating to a diagnosis of metastatic cancer and potential treatment. If patients were to become distressed during the interview, care was taken to stop the interview. It was written into the ethics of the study that if a patient was too distressed and wished to withdraw from the study, they were given reassurance that they could do so and this would not affect their care.

As a nurse specialist, the researcher is experienced in managing distress and signposting to other services should the need have arisen. Additional support for the patient could be sought with the patient's approval e.g. their General practitioner (GP). A study letter was sent to the respective GP of each participant to inform them that their patient had taken part in the study (see Appendix VI). The Clinical Psychology department within the hospital were also in agreement to take patient referrals with a patient's approval, should this have been deemed appropriate. They were also able to offer advice to the researcher if required.

Having had direct experience of the pathway, patients are often keen to share their experience as a way of voicing and making sense of that experience. It may help that they can do this with a researcher, who as a nurse specialist is familiar within the field. In addition, the feeling of being listened to will ensure that they feel they can contribute to change and any possible improvement to the care of future patients.

There were minimal risks to the researcher. When a home interview was conducted at the patient's request, the researcher left details with a colleague of the location. The researcher also had regular supervision from the Clinical Psychology service within the local hospital, should any distressing issues from the patient interviews require to be discussed.

Mason (2002) suggests that when doing qualitative interviewing, there should be moral research practice at every stage.

> *"This means attempting not only to carry out our data generation and analysis morally, but also to plan our research and frame our questions in an ethical manner too" (Mason 2002, p.41).*

In this way, it goes beyond the actual interview and into how data is heard, analysed and presented. Of course, Mason (2002) is quick to point out that despite such good intentions, research can throw up some competing interests which might also compete the ethical stance of the researcher. In such cases, the researcher should keep ensuring that they ask themselves the difficult questions and strive hard to know how to answer them. This analytic approach helps to maintain researcher accountability throughout the study. Indeed, within the last decade, more attention has been given to the emotional challenges of the researcher when dealing with sensitive issues (Hubbard et al 2001, Holstein and Gubrium, 2004) and not just the participant. This has led to the consideration of necessary support measures being embedded in the ethical submission process (Kings & Horrocks 2010) and notes a move away from the traditional viewpoint that it is only the participant who can encounter harm.

5.10.4 Fostering a reflexive approach

Hubbard et al (2001) refer to a challenge that often presents itself when undertaking qualitative research. This challenge often seems like a paradox,

> *"The challenge therefore is how we can construct meaning and develop understanding and knowledge in an academic environment that, on the whole, trains researchers to be objective and 'extract out' emotion." (Hubbard et al 2001, p.136).*

They argue that we are taught to extract out emotion in an attempt to become more objective rather than bear witness to its influence. Avis (2002) grapples with the idea of putting 'self' into research in a useful and, indeed, amusing self-analytical chapter, entitled, 'Making Space for Subjectivities in Interviews'. After much grappling about how to present self, position self, and be self, she concludes,

> *"The practice of reflexivity is one that attempts explicitly to link the idea of self to the process of knowledge construction" (Avis, 2002, p.205).*

The process of being reflexive is inextricably linked to all stages of the research process, writing in the researcher rather than writing out. The idea that knowledge is constructed because of the presence of an active rather than neutral researcher leads Holstein & Gubrium (2004 p. 157) to suggest that "all interviews are unavoidably active meaning-making ventures". This is both a huge privilege and responsibility.

5.11 Skills required for the interview process

Where possible, excerpts from the interview transcription were used to reflect upon the researcher's own interview practice with particpants. In transcripts 'I' will represent the interviewer and 'P' the participant. The words interviewer and researcher will be used interchangeably. I felt that this was important, not only as a way of showing a reflexive approach used, but also as a way of showing transparency in the interview medium.

5.11.1 Entering the shoes of the other

It was the researcher's intention to delve into the world of the participant. Having the time allocated during an interview provides something of a luxury and privilege. Entering into the shoes of the participant takes time and does not happen instantly (Schulman-Green et al 2009, Dickson-Swift et al 2007). It is a gradual process and from the outset the researcher can aid this by ensuring that the participant is comfortable. Much of this may be done off-tape in the initial encounter with the interviewer taking a hospitality role but ensuring the comfort of the participant throughout is something which the interviewer will continue to be aware of.

For some researchers, nothing of the world of the other will be known while others will have some level of existing knowledge about the subject or participant group. Either way, it is important that the researcher sets aside any assumptions or value judgements which they have consciously or unconsciously formulated. For the liver metastases study, the researcher was familiar with the care setting and treatment pathway involved for participants and it was important that open questions were used to enter into their experiences rather than focus on what the researcher perceived problem areas or emotions were. The use of a broad question at the beginning of the interview was used to open up the interview to the participant. The interview transcript reads as follows (after introductions and a brief description of the research, off-tape):

> I: *"If possible, can you take me back to the start and tell me how you were when you were diagnosed, how well you were and what symptoms you had at the time?"*

This question allowed both the researcher and interviewer get off the starting block and provide some safe context in which to set the rest of the interview. On reflection, the question appears to be split into three parts although all parts are essentially seeking the

same thing, that is an entry into what it was like to be diagnosed which could then be opened further. Schulman-Green et al (2009) in their practical paper suggest ten techniques for interviewing the seriously ill at end of life. They offer technique number 6, 'start with safe ground and peel back the layers' in sequence to technique number 4 'develop a sense of the participant'. The ten techniques are of use if they are taken as suggestive rather than prescriptive for they could not be applied in some magical sequence in every interview. Drawing on work by McHale-Wiegand et al (2008) they show that layering less sensitive questions towards more sensitive questions and then less sensitive questions at the interview closure is a way of minimising participant burden but also of the researcher peeling back the layers of the participant's story and the associated meaning.

5.11.2 Encouraging a sense of safety and trust

Choosing an environment to help respect privacy is an initial way of encouraging safety (Kvale & Brinkman 2009). Where an interview takes place in the participant's home, it may be helpful to ask if they wish another member of the family to be present as a way of ensuring safety or as a way of checking the participant's consent to that other member who may assume they can be present.

A further way to establish trust is through the presentation of the researcher and the introductions they make (Hubbard et al 2001, King & Horrocks 2010). As the researcher is a member of the direct health care team, it was important that awareness was given to any power dynamic that could make the respondent feel like there was a correct answer or want to gloss over any difficulties in their care in order to please the researcher. The participant may make judgements about the researcher's position which in turn may put barriers up to data being shared in a more collaborative way (Kvale 2006). In the liver metastases study, the researcher opened by briefly reminding the participant of the purpose of the interview and how the data would be used. The researcher stressed

> I: *"that there are no right or wrong answers, that all views or experiences are important no matter whether these have been positive or negative. The aim is that insights are gained from your experience and as a result improvements can be made to the service*."

Putting the participant at ease from the outset is crucial in establishing trust (Rubin & Rubin 2005, Schulman-Green et al 2009). Asking for consent to audio-record and explain that notes may be taken are all ways to recognise the personal nature of what will be shared. Conveying

interest will show the participant that what they share will be valued. Rapport is widely acknowledged as important in facilitating the researcher-participant relationship (Dickson-Swift 2007, Kvale & Brinkman 2009, Bondi 2013. From the outset it could be as something as simple as making a comment to put them at ease if they have been late due to trying to find a parking space or picking up on a conversational cue in their initial introductions. This rapport is something that is built on throughout the whole interview process. Bondi (2013) in her revealed interview excerpts with Katherine found that the first 15 minutes of the interview was a 'checking out' time by Katherine to establish trust and after that rapport was generated. A similar experience was found by myself as researcher in this study. This was not wasted time, but part of putting the interviewee at ease. Gadd (2004) acknowledges that developing rapport is not always easy to do, especially when the interviewee has known to cause harm, or as Hubbard et al 2001, suggest when we find ourselves not warming to a participant.

Often in the back of the mind of the researcher is 'am I obtaining relevant data?' When data are not forthcoming, it may be because rapport has been affected. In Dickson-Swift et al's (2007) study, participants talked about an uneasiness over the use of self-disclosure in order to build rapport. Each researcher needs to decide the level of self-disclosure they are comfortable with without compromising their position as the researcher. For example, in a study with cancer patients, it may not be appropriate to disclose a personal family experience of cancer or indeed perhaps further, a researcher's own cancer experience. Doing so may take the focus away from the participant and cause them to assume the researcher knows what they are talking about. Equally there may be a time for revealing something of the self and world of the researcher at the discretion of the researcher. In one case, I, as researcher, used an example from another participant to gain entry into a new subject but did not reveal any details of the other participant. This statement appealed to the identity of an emerging group of participants 'out there' which could then be further probed.

> I: *"Another participant in the study was saying (and to what extent you will agree with this, I'm not sure), but she was mentioning how the media can be sometimes quite unhelpful?"*

In this way the virtual rapport of another participant was used to move a subject on and yet continue to build on the existing rapport between researcher and current participant. Interestingly Rubin & Rubin (2005) suggest that a reciprocal dialogue in interviewing does not always have to be equal in order for the participant to disclose their experiences.

When talking freely in an interview a participant may find themselves sharing something they later regretted or did not realise they would elicit at the outset of the interview (Kvale 1996). Towards the end of the interview, the researcher can address this by asking the participant if they are comfortable with what they have shared and if they would like to view a transcript or summary of the interview once completed. In this way they can have the opportunity to reflect on what they have shared and correct anything they did not want to share. This will ensure that the level of trust continues well after the interview into analysis and dissemination of findings. Goodrum & Keys (2007) speak about lack of acknowledgment and how an overly professional approach can be unhelpful especially in dealing with very emotional issues. Probing through the pain can still be done if done with recognition of sensitivities. A continual awareness of patient posture and non-verbal cues will help with this. Should it become apparent that the distress is too great to carry on, it can be agreed to stop the audio recording for a time or to move on to a further subject. After the interview has finished it may be necessary to signpost for additional help. Procedures determined for ethical review should help with this but the researcher will need to consider from the outset what their contact with the participant should be after the interview has taken place (Schulman-Green et al 2009).

5.11.3 Facilitating flow

The ability to listen during interviewing would seem an obvious quality to possess as a researcher but the process of listening actively to the verbal and non-verbal is a recognised skill (Kings & Horrocks 2010). Anyone who has practised interviewing will be aware of the difficulty involved in hearing what the participant has said and being able to respond to it. It is all too easy to be considering further questions to keep the flow of conversation going or thinking over what has been said in relation to the wider research questions (Mason 2002). Attending a research training course will help to develop these skills (Roulston et al 2003) as will undertaking some pilot interviews with similar participants to test out the interview schedule (Bryman 2016c).

Throughout the interview the interviewer will draw on a range of strategies to facilitate flow and elicit data. In the liver metastases study, showing interest through verbal utterances such as “uh, hah”, “right”, “um hum” were used across the interview to display attentiveness. Roulston et al (2003) in their interviews with 12 students undertaking research training found

that verbal utterances featured more than the students had been aware of during the interview and demonstrated engaging emotion on the researcher's part.

5.11.4 Summarising

One commonly used strategy was summarising phrases that Mrs X had said in order to check understanding.

P: *"When I was told about spread"*

I: *"Secondaries?"*

P: *"Yes, I really went in not expecting, …I know you learn to modify your expectations but I really didn't expect that, that day, so...I thought this would be the end of it"*

In this the interviewer clarified what was said to ensure the participant understood they each had the same understanding of 'spread' so that further questions could be asked.

Further in the interview, summarising is used to go deeper into a specific issue of patient control.

I: *"And it sounds like, what's very important is that sense of control because you've worked with Dr B and he's worked with what you want as well."*

This gave Mrs X further affirmation to talk about meaning of control to her in decision making.

5.11.5 Redirecting

Part of the rationale of using a collaborative approach in semi-structured interviewing is that there are some specific data that the researcher is aiming to obtain. Corbin and Morse (2003) speak of the purpose of interviewing and Mason (2002) about using the structure of interviews to access 'situated knowledge'. In this study, the interviewer wanted to move back to a point about diagnosis and redirected the participant back.

I: *"And just to take you back a bit to the time when you were in clinic to see Mr P"*

Again, this was used further in the interview.

I*: "Prior to that when you had initially seen Mr P, how sure were you of a plan in place?*

Both of these examples led the participant back to reveal deeper insights on diagnosis that might have been glossed over.

5.11.6 Incorporating the use of gentle humour

The use of gentle humour can be used to aid interview progression. On one occasion in the liver metastases study the interviewer's phone clattered to the floor and fell apart at a point where the participant was getting emotional when she was talking about the worry a head CT had caused her in thinking the cancer had progressed further than she thought. At this point the researcher said "Don't panic" which was followed by laughter from both and transcribed to show this. On reflection, reading the transcript without the context, it looks like the researcher is saying not to panic about the worry, but in actual fact is really saying everything is under control with the phone and gives reassurance that the participant can continue. Unexpected occurrences will happen during the interview but if dealt with in a reassuring manner, the story of the participant will not be lost.

Humour is often exhibited by participants. Occasionally patients paused to share a funny story about an incident that had happened and that lightened the intensity of the nature of the interview. One participant in Phase 1, a previous submarine engineer, had explained that he was not claustrophobic of the MRI scanner despite being in it numerous times added,

P*: " Well, when you crawl down a 21" tube, hundreds of feet underwater, just to check it's all right, claustrophobia doesn't come into it!"*

On another occasion, a participant in Phase 2 had explained how the consultant had visited her bedside post surgery. She remembers feeling very weak but trying to make light of it when the consultant joked that he didn't know what had happened to her, remarking that 'she looked like she had been hit by a train'. Even at day 1 post surgery, she was able to reply,

P: "Well, you were driving it!"

She remembers the lightness that the incident had brought and on reflection had recognised that such a remark might not have had the same effect with another individual but she knew that her consultant had the connection with her to do so. Such occasions provide not only an insight into a participant's personality which usually correlate with their spoken words and interpretation of events but it also provides a good opportunity to build rapport during the interview process which can open up deeper levels of questioning. The use of humour was

noted as intrinsic to hope by Coloqhoun & Hill (2012) and also through Herth's work (Herth 2018).

5.11.7 Repetition of participant's words

A simple use of repetition of a few words can act as a probe to see if the participant wishes to add anything further. In this case of the study in question, the dialogue flows as follows:

P: *"I felt that I had actually gone back to the beginning and back"*

I: *"Back to the beginning"*

P: *"I thought I had actually gone really backwards, worse than I had ever felt, even at the very start of it and you know, I know that's not anybody's in particular, anybody's fault and I know they were all, they all were very sorry that I was in that situation if you like, but it's, yeah it's pretty devastating".*

At this time the researcher felt it was right to echo back the sentiment offered by the participant which then allowed Mrs X to give a fuller explanation of her meaning. Mrs X paused before elaborating. Knowing how long to leave a pause is a skill which the researcher learns to manage to allow the participant to be forthcoming.

5.11.8 Protecting self as researcher

Interviewing can also reveal difficult emotions for the researcher. For participants and researcher both, emotional unease or upset may occur during the interview and can persist after the interview. The researcher may be exposed to feelings unexpected to them and may feel that they cannot show much of this during the interview for fear of affecting rapport therefore hindering data. Dickson-Swift et al's (2007) paper focuses on concern for researcher during interviewing. After interviewing 30 researchers from the field of public health, issues included managing their own emotions and difficulty leaving the field. They suggest that these issues are related to the process of qualitative research and not quantitative and they are compounded when dealing with sensitive issues. Certainly, the researcher needs to have external support in order to talk through any difficulty arising (King & Horrocks 2010). Regular supervision and colleague support will help with this. In the liver met study, myself as the researcher had access to debriefing offered through the psychology unit. This was deemed necessary as part of the ethical submission. I did come across a disturbing account from one participant of something that had happened during his life. Throughout the interview I was aware I had to prevent my focus from oscillating between

what had occurred through the fault of the participant and the interview structure. At times, it felt the interview opportunity became more like a confessional as he reminisced over his life against the backdrop of his illness experience. It was also a reminder that the participant in the interview is no less like a protagonist in any story. Our empathy does not always follow the protagonist. In the context of care, this is also true and can present challenges for how we deal with certain patient experiences. While I did not need to speak to anyone after this interview experience, it allowed me to reflect on not only aspects of my own character that found this story so difficult but also made me more aware of using skills that would help to protect myself emotionally, should a similar situation occur.

Once again, the data generated from interviews is not neutral. If employing a transcriber it may be worth alerting them to interviews or excerpts that may sound emotionally difficult when heard. This was found to be the case in the liver metastases study as the transcriber expressed it helpful to be forewarned about anything of an emotionally sensitive nature as she tended to get involved in the lives of the participants. This would concur with Kleinman & Copp's (1993) sentiment that we feel the participants are 'living inside our heads" (p.8). We want our data to be meaningful and have impact on dissemination yet often we neglect that we or others involved in the process of transcribing or analysing can become affected too. Shared data is never neutral. Perhaps an awareness that aspects of the research can affect anyone in the analysis process, such as transcribers is required too.

5.12 Analytical approach

Having found a fitting methodology in hermeneutic phenomenology based on Gadamerian philosophy, applicable to the study subject and context of experience of liver metastases pending surgical resection, it was equally necessary to adopt an appropriate analytic approach. The process of analysing qualitative data has often been described as something of a mystical process (Thorne 2000) or as Scheillerup (2008) refers to, while referencing the work of previous scholars, the 'black box' of qualitative research practice (p.164). Yet, with greater emphasis being placed on the value of reflexivity in research practice (Watt 2007), more attention is being drawn to prising open that black and making sense of how exactly findings are achieved. While I have been influenced by the work of Gadamer for reasons discussed in section rather than the work of more modern contributors to phenomenology, such as van Manen, I wanted to choose an analytical method that gave a suggested structure to analysis while at the same time shed light into how the data was analysed. For this reason,

I adopted a more modern analysis method in Interpretative Phenomenological Approach (IPA) and the sections 5.12.1 -5.12.3 will discuss the relevance of this method to the study, and how the approach helped to find meaning to the individual interviews and the focus group. The elements of analysis have been adopted as a relevant guiding factor for the data concerned in this study.

5.12.1 Interpretative Phenomenological Approach (IPA)

Interpretative Phenomenological Approach (IPA) has been developed and introduced by psychologist Jonathan Smith in his seminal article in 1996, as a new way of analysing experience, but also complement traditional methods in quantitative and qualitative psychology (Smith 1996). Popular qualitative methods up until this point had included grounded theory, conversation analysis and narrative psychology (Cassidy et al 2011). IPA has over time been developed by Smith, Larkin and Flowers (2009) to become a methodology in its own right, rather purely a tool for analysing data. IPA is an approach "committed to the examination of how people make sense of their major life experiences" (Smith, Larkin & Flowers 2009, p.1) which seeks to pull four elements together, a detailed examination of participants' "lifeworlds", their experience of a particular phenomenon, how they have made sense of these experiences and the meaning they attached to them (Smith 1996). While IPA began its life in the field of psychology, it has gained notoriety in other disciplines. IPA has been recommended for use in healthcare because of its "practical orientation (Payne, Dean & Smith 2006). The intention from the outset of conducting this study was that it would have a practical use in influencing a service. Having outlined the shape of the study earlier in this chapter, IPA analysis appealed to me as having a transferability from the discipline of psychology to direct relevance to a nursing study that was intentionally practical in design. Cassidy et al (2011) note the attractiveness in using IPA in the clinical setting where there is a particular cross-disciplinary interest. With relevance to this study involving participants with colorectal liver metastases, multi-disciplinary input is key, a concept that has been directly referred to in Chapter 2. IPA lends itself to understanding from the perspectives of the participants but also those involved in the given study context. This analytic approach was again deemed suitable because of several elements of interpretation required. Firstly, the data gained from the participants, secondly that from the health professionals involved in the liver metastases pathway and thirdly the level of interpretation from myself as researcher but with relevant insider knowledge. All of these elements, I felt were critical to building up from the descriptive to the interpretative and were vital to producing a more

nuanced and empathic service provision on review of the initial data. It draws upon three main strands of understanding having a base in hermeneutics, phenomenology and ideography with the result that the uniqueness of individual experience are valued.

5.12.2 The notion of experience

At this stage is it worth pausing to consider the concept of experience being analysed. Experience is somewhat of a complex concept, our lives being made up of a range of experiences. Phenomenology researchers and Smith et al (2009,) in particular would argue that IPA researchers, are particularly interested when the everyday experience take on a particular significance. For some degree, we do this everyday for ourselves. Taylor's (1985) work notes that humans are 'self-interpreting animals' who are active in interpreting events, objects and people in their lives. Evaluating those experiences helps us to make decisions. Smith et al (2009) speak of a hierarchy of experience which can be found in one experience. As we attribute meaning, that experience deepens and can become more significant, having now become an experience. Smith et al (2009) cite Dilthey to demonstrate how the smallest unit of experience grows into something more meaningful.

> *"Whatever presents itself as a unit in the flow of time because it has a unitary meaning, is the smallest unit which can be called an experience. Any more comprehensive unit which is made up of parts of a life, linked by a common meaning, is also called an experience, even when the parts are separated by interrupting events." (Dilthey, as cited by Smith et al 2009, p.210).*

It is this comprehensive unit of experience that I was particularly interested in for those who were considered for liver resection. On observation of the pathway to potential liver resection, there is a comprehensive unit of experience centered around whether or not an individual will make it to resection. For me, this was the identified common meaning, but it was unknown what other meanings individuals themselves attached to this period of time. As was outlined in Chapter 2, this period of time could span over many months so Dilthey's recognition of parts of an overall experience being separated by interrupting events seemed fitting to place in the context of the analysis. Unravelling the patient experiences recounted in the interviews could lead to a spiraling out effect of the experiences hidden from the everyday vantage point as health professional and help to reshape some of the service for future patients. Incorporating the data from the health professional focus group could also

lead to a layering up approach which would provide valuable combined insight. IPA recognises that the data shared by participants is dependent on what participants share with the researcher so that in turn the researcher needs to interpret participants accounts in order to understand their experience. In this way a double hermeneutic occurs where the researcher is actively employed in sense making of what the participant is also making sense of from within their framework of understanding.

5.12.3 Finding shape

Producing meaning is an iterative and complex task, despite what would be considered in quantitative terms, a relatively small sample group. The interesting and perhaps surprising fact is that IPA, as with other qualitative analysis does not provide a one fit single method for working with data. Smith et al (2009) realise that for the novice qualitative researcher this non prescriptive means can be a daunting realization, however it is exactly the lack of a prescription that allows one to analyse the data with integrity.

5.12.4 MAXQDA

Qualitative research can generate a huge amount of data which requires management not only for working with but also as a means of producing an audit trail to assist with issues of reliability. In order to assist with organising the data from a pragmatic approach, a qualitative computer programme was utilised. Having undertaken practical instruction on NVivo and entered a couple of interviews onto this programme, I shortly after became aware of the qualitative software named MAXQDA (MAXQDA 2020). I found the format of MAXQDA more intuitive to work with than NVivo which I had been aware of through reading and a more formal introduction to on a number of taught qualitative courses. I purchased MAXQDA plus, an extended version of MAXQDA. This allowed me to store audio files, transcripts and field notes and other relevant notes in the one place. Of practical importance, the data could also be analysed in a four-screen window, enabling ease to apply codes and memos. The benefit of MAXQDA was that it included a MAXDictio mode enabling searches on particular words whereby vocabulary and word frequency analyses could be conducted to help support or create particular codes or themes themselves.

5.12.5 Returning to Gadamer

As outlined earlier, Gadamer placed emphasis on the value of language as a key to understanding human experience. Through the common feature of language, a way to enter

into the world of another is made accessible. Gadamer placed important emphasis on language presented in written text which could then be interpreted, although hermeneutics has now developed beyond purely written language.

> *"Gadamer frames reading and writing not as mastery of language or literacy skills, but as engagement with 'what is at stake'. (McCormack 2014, p.58)*

For Gadamer, we are beings immersed in language. It is our everyday medium and a rich source of understanding. Gadamer argues that it is through language the world is opened up for us. The language contained within the data is under examination and IPA is deemed as a suitable analysis method to examine the research questions at stake. This links well with Gadamerian philosophy as an important element of both is the moving between the part and the whole. That is each part of the sentence will have meaning as well as the whole.

Looking at the transcript text can be done in the context of the whole transcript, i.e. what is being said in the whole interview. Each interview can also be viewed as part of what is being said overall and likewise each section or each sentence as part of the individual interview. This is reflective in the layering up approach of data through the use of IPA. Analysis also brings alive the Gadamerian dialogue between our own pre-understandings and newly emerging understandings from the participant's world where the two collide. The medium for this is analysis. This is going on all the time, through dialogue with the participant during the interview, through rereading the text and field notes, and through the more systematic process of analysis, in this case IPA. This fusion of horizons (Gadamer 2013) aptly fits with the merging of participant interviews, health professional views and the interpretation of the researcher in this study.

5.13 The process of analysis

Thorne (2000) describes data analysis as a process that essentially transforms raw data into new knowledge. It does indeed sound a magical effortless process but the resounding question as a researcher and particularly a novice qualitative researcher is 'how?...how does that process work?'. Thorne is clear that analysis is something that the researcher must engage in throughout all phases of their research. It is active and engaging and she would suggests that it would be a mistake to limit it to one section of the overall research, i.e. the

bit that commonly gets labelled as data analysis. Ziebland & McPherson (2006) echo this sentiment. When researching the researcher's mind is often full of questions at different time-points. Without realising it, analysis is a continual process all the way from deciding on a research question, recruiting participants, handling raw data and reporting on the findings. For this reason, I tried to transfer as much of my thinking into MAXQDA as well as the interview transcripts in order that as much as the context of the research was close at hand and visible to me. The documents transferred to MAXQDA were:-

- Research proposal containing background to study and research questions
- Interview schedule
- Typed field notes of hand written field notes from four interviews
- Summary of interviews
- Transcript of interviews
- Audio files of interviews

This meant that all the documents could be stored in their 'electronic filing cabinet', aptly referred as by Fielding & Lee (2002) for easy access and cross reference. There is much written about good data management or a 'tidy filing cabinet' and the benefit of this particularly evident when dealing with a large dataset (McLellan et al 2003, Franzosi et al 2013). The transcriber was experienced in transcribing in health research and to ensure that the transcript was reliable, I listened to the audio recording while reading the transcript. Wainwright and Russell (2010) stress the importance of this when the researcher and transcriber are different. This way any additional punctuation could be added and some of the 'unheard' communication could be annotated onto the transcript at particular points. In this way I was able to be taken back to the time of the interview and also to aid with the familiarisation of data. During this familiarisation process, I reread the transcripts and then I reread sections in their context, working to annotate on a 'golden paper copy' and also make further notes on additional paper. Having done this, and now beginning to get a grasp of what was contained in each interview, I was then in a position to reduce the data in a precis of each transcript. This very much echoed the summary written after the time of interviewing and recorded in the memo. At this point in analysis I had reached a descriptive phase where I could adequately explain what the key features of each interview was but only by coding in order to generate themes, could I begin to deepen the analysis (Ryan & Bernard 2003, Richards 2015). Although their publication is written with NVivo in mind, Welsh (2002) provides some helpful advice, commenting,

"It is important that researchers recognise the value of both manual and electronic tools in qualitative data analysis and management and do not reify one over the other but instead remain open to, and make use of, the advantages of each" (Welsh, 2002, para. 12).

Smith et al (2009) helpfully point out six steps to analyse data, detailed in Table 5.6 overleaf.

5.13.1 Coding for emergent themes

In the CAQDAS software, MAXQDA this is done through selecting sections of text/words and placing them at nodes. These act as a gathering point for specific areas of interest (Bryman 2016d). Development of the codes was for me a dual process between paper and working with the documents in MAXQDA. This use of paper and screen allowed me to look at the data differently. Working within the area of research, it was tempting to assume that I had a clear sense of what the codes were but I resisted the temptation immediately to use *a priori* coding in order see what was striking about the data and as an attempt to let the data speak. I found the section entitled 'What to look for when you are coding' in the online article by Taylor & Gibbss (2005) especially useful to bear in mind when attributing data at codes.

Following this I coded according to my four main research questions and then topics from my interview schedule. What is especially helpful about working with MAXQDA is the ability to have imported internal documents alongside research data to work closely with them. Finally, I coded according to words that 'sprung out' at me after having familiarised myself with the data, such as 'secondary', 'choice', 'hope', 'futile'. Putting all this together I ended up with 35 codes. In order to make sense of these codes further, I began aggregating them under parent codes and could then see which codes were redundant. This process left me with 15 codes as displayed in Table 5.7 overleaf. Each of these contained at least 2 sub codes. Deciding which code to attribute a text to is up to the judgement of the researcher. For example, placing a perceived attitude of a medical team member, could fall either into code 03 or code 07. I found that noting a description of the code in the properties box was helpful. In addition, importing a codebook into MAXQDA would also prove useful and could allow for greater transparency of analysis trail and thinking when printed.

Step	Name	Characteristics of step
1	Reading and re-reading	Entering the participants' world. Making the participant the focus of the analysis.
2	Initial noting	Produce detailed set of notes and comments on data. Descriptive comments, Exploratory comments, Linguistic comments, Conceptual comments. Deconstruction. Produce overview summary of initial notes.
3	Developing emergent themes	Turning data and notes into themes. Themes reflect participant data and researcher's interpretation – a synergistic process of description and interpretation.
4	Searching for connections across emergent themes	Map how themes fit together. Use methods such as Abstraction, Subsumption, Polarization, Contextualisation, Numeration and Function if helpful. Result will be themes and super-ordinate themes from one participant.
5	Moving to the next case	Repeating the process. Maintaining initial distance from previous case.
6	Looking for patterns across cases	Examine connections across cases. Reconfigure/relabel/ discard themes. Developing levels of interpretation.

Table 5.6: IPA suggested steps for analysis (adapted from Smith, et al, 2009)

Workable master codes

Workable codes	
01	diagnosis
02	recovery from primary surgery
03	relationship with medical team
04	Relationship with specialist nursing team
05	Side effects of treatment/chemo
06	imaging
07	changing nature of scans
08	communication
09	managing other conditions with secondary cancer
10	managing life with secondary cancer
11	Information
12	social/family relationships
13	external support
14	use of language with strength of feeling
15	tensions in pathway

Table 5.7: Example of coding

5.13.2 Advantages and disadvantages of using CAQDAS

One of the features of MAXQDA of which I was particularly interested in, was its ability to demonstrate transparency in how findings were achieved. It is harder to do this with a pen and post-it notes, although one might argue that in order to achieve true transparency, the researcher might need to give their software up for perusal in conjunction with their findings. Nonetheless, working with CADQAS software allows the researcher to keep track of their own thinking and the linkages made with data. This is surely an attractive feature and should contribute with representative reporting of findings and aid issues of reliability and validity (Kelle & Laurie 1995, Gibbs & Managabeira 2002, Franzosi et al 2013). In addition, Robertson (2008) advocates using CADQAS software to map the overall process of the researcher's journey to recall thought progression and improve transparency. If a strength of MAXQDA has been its efficiency to code, so too is it a weakness (Welsh 2002, Bryman 2016d). I did find that I could easily code more than I required and even have enough data for two different research studies, something commonly known as the 'coding trap' (Richards 2015, p.118). Working with the research questions and interview schedule helped with this as too did checking the coding stripes tool. Using personal judgement and knowing when to stop are skills the researcher must exercise (Richards 2015).

Other less favourable aspects of computer assisted programmes are a feeling of being slightly removed from the data (Bryman 2016d) as computer management can attribute a clinical feel. This may be the case especially when using CAQDAS for interactions in focus groups as reported by Catterall and Maclaran in 1997 (Bryman 2016d). Attention to data organisation will help to hear the individual voices within the focus group. In addition, electronic software, can be prone to computer glitches, crashing and loosing of data, making back-up of work essential. While CADQAS software it extremely beneficial, it cannot replace the thinking ability of the researcher as Goble et al (2012) conclude,

> *"Analysis will always be bound by the researcher's abilities; while computer programs may enhance those abilities, they will never replace them." (Goble et al 2012, para. 4.*

As analysis develops, the researcher looks for patterns/themes in the codes (Bryman 2016b). These themes are essentially recurring patterns of meaning that are likely to identify an area of concern to the participant (Todres & Holloway 2010). After an initial list of themes were created, they were clustered into connected areas. These were then divided into main

themes, super-ordinate and sub-ordinate themes. The themes from both the patient interviews and health professional focus group were then used to drive forward a service change and plan targeted nursing intervention in the interim phase as follows in Chapter 6.

5.14 Chapter Summary

This chapter has discussed the chosen methodology of hermeneutic phenomenology as influenced by Gadamerian philosophy as appropriate to the study context of the experiences of those undergoing liver resection for a colorectal metastases. Consideration has been given to the skill set required for conducting interviews of an emotionally sensitive nature, and the reflexivity required as a researcher during and after the interviews have been conducted. An overview of the practical and ethical considerations have been examined and the suitability of Smith et al's (2009) Interpretative Phenomenological Analysis also has been established. This methodological chapter sets the framework from which to view the results of Phase 1 in the following chapter.

Chapter 6

Seeing different horizons - findings from Phase 1

"The real being of language is that into which we are taken up when we hear it — what is said". (Gadamer, (1966) as translated by Linge, 2008 p.65)

6.1 Chapter overview

This chapter will present the findings of the sixteen interviews and the focus group from Phase 1 of the study. It is the result of the immersive and labour-intensive process of analysis as outlined in Chapter 5. It aims to take the reader back to the interviews, as if they were there, back to the events, language and phenomena described. To this effect, this chapter has a different feel on reading. As a health professional with an insider vista, so much of health care is reactive and fast paced. Decisions are frequently made on assessment of large amounts of assimilated information, either in response to a patient's condition or in response to current evidence and protocols. The day to day environment affords little time to understand the experiences of those we care for or those we work alongside. Both the interviews and focus group from each phase have provided an opportunity to gain insight into the experience of a known group of individuals. The interviews lend the occasion of being able to actively hear the experience of being considered for surgical CRLM resection, while the focus group allows the experiences of a group of health professionals to be aired in relation to this pathway. In contrast to the often, frantic daily nature of health care the interviews and focus group have offered the opportunity to 'slow things down' and reflect on the nature of experience. As a researcher with insider awareness of the CRLM pathway, it is recognised that assumptions need to be set aside as to what that experience might be, as eloquently expressed by Gadamer in the opening quotation of this thesis.

With insider knowledge of any given health care pathway, it may be tempting for health professionals to pre-empt or claim knowledge of what issues may arise for patients but we are not the patient and our experiences are not theirs. The findings presented are that attempt at giving a voice to those experiences without second guessing them in order to understand the CRLM pathway more fully, while at the same time acknowledging the role of interpretation that a researcher with insider knowledge has in the overall process.

As Smith et al (2009) suggest, there are different ways of structuring the findings of phenomenological writing when Interpretive Phenomenological Analysis (IPA) is used. One could see that the linear process of beginning, middle and end might fall neatly into disease, treatment, outcome or that the disease trajectory may be relevant as treatment decisions progress or different stages in the pathway might be appropriate. Other options may have been to look separately at the data from those who were able to proceed to liver resection and those who were not or to concentrate on the interviews and then to deal with the health professional data as a distinct group. While all of these options might have their place, three things shaped how this section was written. The first, was that I wanted the writing to reflect the whole of the pathway experience rather than be guilty of dividing the pathway up into how I might tend to view it as a health professional. This was important in the context that it was possible for the liver resection to take anything from three months to beyond a year when a staged bowel and liver resection was indicated. The second, was that the analysis itself dictated how the data was to be presented and indeed supported my view that the whole of the pathway experience should be represented. The third was that in line with the appropriate methodology chosen, the findings ought to represent a fusion of horizons of different viewpoints which was why it was important to include both the views of those individuals who had not proceeded to liver resection and the perspectives of health professionals involved in the pathway. With this in mind, the analysis yielded three master themes which were linked to three horizons of understanding;

- a path of expectation: an enduring horizon
- the companion of uncertainty: a unified horizon
- a journey of personal understanding: an individual horizon

The table overleaf details the overall themes, stemming from the three horizons.

From the master themes follow a number of superordinate themes and sub-ordinate themes. Sub-ordinate themes could sit independently as themes in their own right but flow from the superordinate themes. The themes are described and exemplified with extracts from participants and blended with analytic comments. In this way a narrative account follows which has been fused with the personal experience of the participant and the interpretative input of myself as researcher. When the term Phase 1 is used, this relates to Pathway A prior to the initial study findings. The discussion in Chapter 9 will pick up more fully on these concepts together with the findings chapter 8 from Phase 2. Pseudonyms (first name only) have been adopted within this chapter to protect the anonymity of participants. The use of

pseudonyms reflects the use of phenomenological methodology in giving a more personal quality to the experiences presented.

Master theme	Super-ordinate themes	Sub-ordinate themes
1. A path of expectation: an enduring horizon	1.1 Travelling with the backdrop of diagnosis	1.1.1 Transitioning the diagnosis: from the well to the not so well 1.1.2 Confronting a doubly shocking diagnosis 1.1.3 Questioning in the context of 'me'
	1.2 Hoping for chances: desiring life, desiring time	1.2.1 Looking forward to possibilities in medicine 1.2.2. Acknowledging: There is no choice 1.2.3 Treating with curative intent means an active wait
2. The companion of uncertainty: a unified horizon	2.1 Health professionals: guardians of the CRLM pathway	2.1.1 Oncology: a place of safe keeping 2.1.2 Nurse specialists: a welcome companion
	2.2 Reliable information: a remedy for uncertainty	2.2.1 Struggles of communication give way to fear 2.2.2 Language has a memory 2.2.3 Uncertainty: a forever friend
3. A journey of personal understanding: an individual horizon	3.1 Unintended journeys	3.1.1 Understanding looks forward 3.1.2 Gratitude gives back
	3.2 Arriving	3.2.1 What matters most 3.2.2 Keeping hope alive

Table 6.1: Master and corresponding themes from Phase 1 analysis

Understanding of data comes from understanding part and the whole. This happens on two levels. The use of IPA as a methodological framework allows dual aspects of interpretation by participant and by researcher. Through the process of data analysis, it can be seen that the patient is both participant and interpreter and the researcher is viewed as both observer and interpreter. Analysis is an attempt to understand what it is like to stand in the shoes of the participant. As Pietkiewicz and Smith (2014) outline, analysis is both descriptive because it is concerned with how things appear and interpretative because it recognises that there is no such thing as an uninterpreted phenomenon. While the participant might share what they know of their experience, Gadamer holds that the we (or in this case the researcher) will

interpret this experience with any foreknowledge or background to that situation or indeed any prejudices they may hold (Gadamer 2013). This is an important reality to be aware of during interpretation, particularly with the pre-knowledge that I had of both colorectal cancer and the liver metastases resection pathway. For me, looking at interpretative meaning through horizons was significant as it signified pulling all viewpoints including my own, together to arrive at a more complete sense of meaning. As Gadamer states,

> 'The concept of horizon suggests itself because it expresses the superior breadth of vision that the person who is trying to understand must have. To acquire a horizon means that one learns to look beyond what is close at hand – not in order to look away from it but to see it better.'
> (Gadamer in Nixon, 2017, p.30)

While any one patient account could give a rich narrative insight into the experience of being considered for a colorectal liver resection, it was the pulling together of these horizons of experience together with the horizon of those used to stepping back and seeing the whole pathway, i.e. the health professionals that would give I felt, as Gadamer expresses, that 'superior breadth of vision'. In addition, as a health professional familiar with the service, I had to 'learn to look beyond what is close at hand' with the intent of an improved line of vision and understanding.

6.2 A path of expectation; an enduring horizon

> *"Human life goes on this way in very diverse expectancy, expecting very different things according to different times and occasions and in different frames of mind, all life is again one nightwatch of expectancy". Kierkegaard 1844, p.206*

Life is a rhythm of expectancy. The above quotation taken from Kierkegaard's discourse entitled 'Patience in Expectancy' Kierkegaard (1844), highlights the rolling, seasonal nature of expectancy in life, stating prior to this reflection, that expectancy *"will not cease as long as time separates and divides mortal life*" (p.205). Perhaps due to our expectant nature as humans, we are always looking forward, always capable of planning our lives and what might come, but it is harder to do this when life takes different directions that we had not planned. There may be less resistance to expectancy when life is going well but Gadamer's philosophical interest had been with understanding what happened when life events did not work out as expected and how we navigated life in such circumstances. Working within the colorectal cancer team and encountering patients who are being considered for liver

resection, is a clear example where life has not gone as planned. There is no doubt that this could certainly be said of any cancer diagnosis, but my interest lay in uncovering the experiences of this particular group with metastatic disease where the tension sat between the possibility of liver resection in the hope of extending life or possible cure and the knowledge that without resection, the diagnosis was certainly terminal. These tensions only occur because of technological surgical advances often combined with developments in systemic anti-cancer therapies which have given rise to new opportunities in treating colorectal liver metastases. With this in mind, it is easy to perceive the weighty significance that an associated liver resection can have for an individual and their families and friends.

An overarching theme of the experiences of the CRLM pathway has been one of anticipation and expectancy. As a noun, a definition of 'expectancy' is,

> *"The state of thinking or hoping that something, especially something good, will happen." (Oxford University Press, 2018, online, paragraph 2)*

The English Oxford Living Dictionaries focuses on current word usage and practical usage which holds a subtle helpful element here. Many other definitions primarily connect expectancy with something good but this definition conveys the idea that the something good may not always follow through but that ultimately there will be a turn of events when something will happen. It is this idea that is seen in the liver resection pathway. The 'something' is when the possibility of being considered for liver resection over a period of time is either achieved or not achieved by way of resection. This was epitomised for me by two individuals by the following phrases that were spoken during their interviews.

> *"I knew up front what my hopes and expectations were. I didn't worry or panic once I knew that this was the road I was on you know, there's no alternative, you know." (Chris)*

and

> *"I was on this track, happily following it if you like. There was no reason to go beyond that." (Julia)*

Chris proceeded to liver resection and at the time of writing remains well, almost 5 years after his liver resection, while Julia, sadly, was not able to proceed to liver resection, having had further imaging which upstaged her liver disease after chemotherapy rendering her liver to be inoperable. She died approximately a year after her interview. The expectancy and hope that something could be done whilst not always knowing what that something was or

if it was possible is expressed through language and a tangible raw but reflective emotion throughout these interviews.

As such this whole period from diagnosis of liver metastases to determining the possibility of resection becomes a journey filled with expectancy. The following sections will reveal the super-ordinate and sub-ordinate themes that sit within this first main theme to be presented, 'a path of expectation.'

The interviews began by asking the participants to tell the researcher something of the background to their diagnosis of both the bowel primary and the secondary spread to the liver. As highlighted in chapter 5, the format of the interviews used an aide memoir to allow for some semi-structuring of the interviews if needed. The reality was that very few participants required semi structured questions asked during the interview because they told their story of their experience of being considered for liver surgery with the natural flow of a story set with a beginning, middle and ending which was often neatly married up with a timeline of a diagnosis, treatment and outcome of treatment. Of the twelve who proceeded to liver surgery, ten were diagnosed with a synchronous liver secondary occurring at the same time as their primary bowel cancer. Of the four participants where liver surgery was considered but not possible, three were diagnosed with a liver secondary at the same time as the bowel primary. This means that only three of the participants had liver metastases detected during a period of follow-up under follow-up surveillance. However, what was evident from the interviews was that the spread to the liver was often wrapped up and inextricable from the original bowel primary. As a researcher, the interest and focus was on the secondary spread to the liver with an acknowledgment that this had come from the bowel whereas, as a patient, were it not for the fact that there had been a bowel cancer in the first instance, there would then be no liver secondary. As such the conversation around the getting to the liver diagnosis often batted back and forth in relation to their primary tumour diagnosis or diagnosis of synchronous liver metastases. Two sub themes which sat within a *path of expectation: an enduring horizon* were travelling with the backdrop of diagnosis and hoping for chances; desiring life, desiring time.

6.2.1 Travelling with the backdrop of diagnosis

While the general notion of going on and forward with a treatment plan was apparent there was an awareness that travel forward was done against a backdrop of the original diagnosis. The original diagnosis was either the primary tumour or when secondary spread to the liver

was discussed as part of that original diagnosis. For the three individuals who had a liver metastases diagnosed during follow-up, their initial thoughts went back to diagnosis of the primary tumour as revealed through the following quotations;

"I remember getting a vibe from the endoscopy nurse. She said something like 'not to worry that things would move quickly when I was in system'… I remember thinking 'that doesn't sound good if things need to move quickly." (Helen)

and

"I had felt well so it was a shock when it [the diagnosis] came." (Scott)

These quotations transport the reader back to the time where the realisation that a primary bowel cancer had been detected. It was only later after primary bowel surgery and during follow-up that a liver metastases was detected. The realisation that something is wrong often unfolds to the individual before confirmation, as evidenced by Helen while Scott reveals the commonly felt emotion of shock with a cancer diagnosis. This shock was intensified particularly when Scott had no symptoms. Very often as highlighted by Helen, the idea that we want to reassure individuals can actually accentuate that feeling that something is wrong. This was also expressed by another participant who recalls going to their GP due to frequency of bowel function and later diagnosed with synchronous bowel and liver cancer.

"When I think back, my GP was very diplomatic and I thought she must have thought this sounds like bowel cancer but we will not worry him and we'll say, 'oh it could be a thousand and one things'." (Chris)

This wandering back and forth in discussion throughout the interview was something that I remember during the interview being quite concerned about as if perhaps the interviewee hadn't grasped that the discussion wasn't predominantly about their diagnosis. This is a good example of seeing the actual interview as one part of the overall hermeneutic process in interpretative phenomenology as it is only when the analysis occurs that my fears were relieved. There were three common sub themes that ran through this theme of looking back to the context of diagnosis. These were intermingled with thoughts about being prepared for liver resection. Clark (2008) writes that both doctor and patient come into a consultation with a different horizon. As is often evidenced in the clinical setting, it may be difficult to move a patient onto a new horizon of thinking because they are still caught up in the adjustment to the diagnosis. Annis (2018), herself identifying as a breast cancer survivor remembers the day of the diagnosis, when

"cancer came in like a wrecking ball to shatter my life into little pieces" (Annis 2018, paragraph 4).

Certainly, while the focus group acknowledged the impact of diagnosis, there was more time taken up with the diagnosis in the patient interviews as it represented a significant time point where life as they knew it changed.

6.2.1.1 Transitioning the diagnosis; from the well to the not so well

During the interviews, there was recognition regarding a point where events in participants' lives changed to alert them that there had been a change in their health. This was a precursor to the actual diagnosis of bowel cancer before acknowledgement of liver involvement. For the majority there were small signs that echoed their own suspicions regarding their health during the process of diagnosis and associated tests. Looking back in the knowledge that this was bowel cancer, this process was part of the rationalisation that something in their health was not right. Apart from those who had presented as an emergency, all the participants reported feeling well. One participant explained, how on completing the bowel kit given to him by his GP, the speed at which the results were relayed back had confirmed his suspicions that something was wrong.

"You know there is something wrong when a motor cycle outrider appears at your door and makes you sign for it." (Robert)

He went onto explain that after colonoscopy he knew that he knew something was amiss as he was one of the last patients in the day bed suite waiting to speak to a doctor.

"Everyone else was gone and I was held back and they've taken blood samples from you so you know that there is something seriously wrong." (Robert)

For the majority this transition was a gradual process where signs along the pathway to diagnosis gave way to more concrete feelings that something was going to change in their health. An important part of the transition process was the acknowledgement of symptoms. The symptoms alerted individuals to the fact that something was not as well with their health as it should be. Nine out of the sixteen patients did present with symptoms to their GP, although these symptoms were not always initially attributed to bowel cancer as the following participants recall. The interesting thing was that patients did often realise they reported symptoms of bowel cancer with three citing food poisoning, irritable bowel syndrome or piles as the reason for their change in bowel habit.

Conversely other patients, despite reporting symptoms, felt that either previous tests or being well had inoculated them to some degree of the possibility of concern.

> *"It took me by surprise because my GP had said 'there was nothing to worry about, it will not be anything sinister because we've already had that clear colonoscopy'." (Amy)*

Interestingly two patients reported that they did not have any symptoms to alert them immediately prior to diagnosis. Both patients had their original bowel primary detected through the National Bowel Screening Programme. However, it later emerged during the interview that they both had experienced symptoms, one of weight loss and the other of bleeding.

> *"I don't know what happened in the past before my operation. I was 14.5 stone but I went down to 13. My wife used to make my tea and I could hardly eat it and I was quite happy with a sandwich. Something must have been inside me that was making me lose my appetite and when I got told this, this could have always been to do with it." (Craig)*

and

> *"I had nae problems with my bowels or that…but a year ago before it, I passed some blood but they thought it was just piles and that and they gave us a steroid." (Alex)*

On reflection, the manifestation of symptoms, helped individuals to move from the 'well' to the 'not so well'. Symptoms particularly were seen as an invasion into the normality of life. One partner echoed her husband's sentiments when she described the abruptness of the transition from life as they had enjoyed it, to a different reality.

> *"It was all so sudden…from my point of view it was quite traumatic and it was quite a shock because we were ticking along very nicely up until that point and then suddenly bang, you know, so that shock took a little while to recover from." (Wife of Andrew)*

This was particularly the case when individuals were admitted as an emergency as Andrew had been following acute abdominal pain. Due to this there was little time to process the speed of transition to becoming unwell. This was a different picture for another participant when the diagnosis took place following primary bowel surgery, although the feeling of not being 'well' after surgery raised some suspicion,

> *"I came back for follow-up every three months, but looking back I never actually felt well in myself after the surgery. I couldn't quite pin point it.*

My mother had bowel cancer but it had spread to the liver at diagnosis. It was different to me." (Helen)

There is the realisation through all of these that individuals realised that they were moving through a transition stage in their health but it was the diagnosis of liver metastases that gave individuals the greatest alarm. Perhaps this was because the majority of this sample group had synchronous liver metastases diagnosed at the same time as the bowel primary. It may also be because of the weight of significance of what metastases meant as conveyed in the next section.

6.2.1.2 Confronting a doubly shocking diagnosis

Two participants spoke about how difficult it was to have been diagnosed with liver metastases in a follow-up period after the bowel primary had been dealt with.

"The news of the liver was horrific. I said before how my mother had bowel cancer diagnosed and later in lymphatic system. She had a liver resection. From beginning to end she lived for six months. After the liver resection, she went downhill very fast, that was why it was so horrific, from that perspective, what going to happen to me?" (Helen)

and

"It was a bigger shock than even the bowel, because the bowel was cut out, you thought that was it, all dealt with so it was a bit of a shock when it was in the liver." (Alex)

For those with synchronous metastases, the following quotations highlight how difficult it was to comprehend the double diagnosis of both bowel and liver.

"It was Ms x (surgeon) who told me that there was a liver tumour as well. It was quite shocking…I just sat there totally shocked, it was not what I was expecting." (Amy)

"It was slightly like getting hit with a shovel I suppose. It wasn't just about the liver but just the shock in general and it being confirmed that you have got cancer." (Richard)

"The biggest shock was the second, the liver one…that was a shatter because when he [oncologist] said, I was sort of freaking out in the sense that it is spreading and he assured me no." (Lauren)

"I got the bad news from him, [surgeon] that it had already spread with secondaries in the liver...I thought what on earth is going on here, I couldn't quite grasp how it had gone from 0-7 in one fell swoop really with no symptoms." (Julia)

There were those who spoke of secondary spread to the liver and the instant association they made with death as they struggled to make sense of what this meant for them or their families. The significance of secondary spread was understood to have had a gravity more so than had there been a primary diagnosis alone.

"You think its spread to other parts of my body, this is what they are telling me, this is a death sentence, that's what your mind does." (Robert)

"A secondary in your liver and I said what does that mean? To me secondaries oh doom, doom, doom." (Lynn).

"You're going to die ay? Well that was what you were saying, that was the thing you thought, am I going to be on a time limit here?" (Wife of Craig)

For these participants at this time, it was harder to see a plan or way ahead. Conversely, there were others who reported feeling a more controlled response to the news of the liver metastases.

"Because I was told the spots on the liver were small, I didn't worry at the time" (Paul, no op)

"I was on my own when I was told... I knew I was strong enough and I didn't want anyone else to be hurt if that makes sense. At a phone call from my consultant after this time, my partner was saying what's the prognosis?. Well it was 1:5, more on the bottom end of the spectrum so it's no looking too good but I thought, ok, I can live with that." (Tom, no op)

"After going through what I'd just been through, I thought oh well, looks like I've got to go through another op and after having all the ops I've had on my neck, and stuff like that, it's, I'm not being blasé about it, but it just, I just thought well if it's got to be done, it's got to be done." (Andrew)

"Och, it was upsetting, but I just had to accept it and just hopefully everything is going to be alright and that." (Craig)

The more philosophical approach to the reality of liver metastases, may have been partly due to individual personality and previous life experiences which may have shaped any reaction to such news. An interesting paper over a decade ago, reports how older adult cancer survivors were able to draw from previous life experiences and bring something positive to their cancer diagnosis (Towsley et al 2007). Difficulties may become apparent when coping styles that have either not been used effectively or are not adequate are brought to the new situation such as a cancer diagnosis. The nurse specialist is well placed to help patients

recognise and utilise individual coping styles to help manage uncertainty in the adjustment process.

6.2.1.3 Questioning in the context of 'me'

Patients revealed their thoughts of how they had come to have bowel cancer by either the context of family history or lifestyle choices. This also affected how they perceived their outlook on treatment. Of those interviewed, seven reported a family history of cancer which they saw as either important for how they viewed their current situation or how others in their family perceived it. Four of these seven, had a first degree relative who had bowel cancer. This could act as something that individuals had to 'fight' against as the first participant so vividly describes;

> *"I said before how my mother had bowel cancer with lymphatic and liver metastases. She had a bowel resection and from beginning to end she lived for six months. She went down hill very fast. That was why it was so horrific. From that perspective, what was going to happen to me? When I had to tell my brother, I knew he thought the same as me, the same scenario. My mother, couldn't accept it but my attitude was different." (Helen)*

In this way, there was an extra burden that the patient also carried, knowing that her brother also had this experience and feeling some of the pressure from that relationship. Later in the interview she went on to describe how because of her brother's ongoing concern, she had to pull away from him to some degree as she felt the negativity that came out through concern was not helpful to her. Similarly, one patient had a similar 'battle' when his sister shared a friend's take on his situation.

> *"Unfortunately, I had lost a sister to leukaemia. I think some doctor friend of a sister said 'oh that's not good', he's got secondary cancer' and they weren't aware of the cure, so my sister was thinking I was on the terminal list but I didn't believe that from day one anyway." (Chris)*

In both cases, both these individuals managed to find the psychological strength to pull away from these thoughts at diagnosis and frame their situation more positively or as Chris indicated, refuse to give in to the idea that he was on the terminal list in the first place. This all pointed to the fact that they hoped for something else, which is linked with the findings in Section 6.2.2. Conversely, one patient admitted that as his sister had been through cancer and that she became a point of guidance and support,

"My sister had a similar op to me for bowel cancer. It was easy just to phone her up and say 'look sis, I've got bowel cancer and she said don't worry about it." (Andrew)

Two patients also shared their belief that stress in life had either caused led to their cancer or had certainly led them to not become aware of changes that were happening in their bodies which might alert them to seek help.

"My husband was diagnosed as terminally ill and it was a very stressful time. I was his main carer and I was working full time. After his death, when I was about to go back to work, I suddenly realised physically that I wouldn't be able to make it from the car park to the office and I realised that this was not mental but physical. I think in hindsight I had focused so much on the last year that we had together that I did not see I was becoming unwell." (Scott)

and

"Looking back, I had been under a lot of stress at work. I'd ran the business for 27 years and I really do wish that I hadn't put the company into liquidation. I was so involved and had carried on with the business, perhaps not seeing the signs. It was very stressful and I'm a great believer that stress has to come out somewhere. I know there are no proven links with stress and cancer but things might be a lot different if I had of taken care of myself." (Chris)

Finally, Steven twice throughout the interview came back to discuss arthritis tablets that he believed he had been left on too long by his GP, believing there to be a link between this and development of his bowel cancer. What was of interest was that all of these examples look back to a time to explain how they arrived at where they were when interviewed. They do not look back to go forward, nor does it hinder their going forward but they all carry with them a backdrop of their diagnosis that provides the context as to how they got to be considered for liver resection. The diagnosis period holds vastly different meanings for individuals and health professionals but becomes a starting point for understanding potential treatment. Clark (2008) when considering Gadamer's fusion of horizons, writes,

"Understanding' is the fusion of our past and present horizon" (Clark 2008, p.3)

In this way the past, present and future co-exist. We cannot have one without the others. The very fact that the present could not be formed without the past is why the diagnosis period comes and out of focus during the interviews. It is important to acknowledge in that it may also set the context for issues that arise in the rest of treatment.

6.2.2 Hoping for chances: desiring life, desiring time

While the diagnosis formed an anchor point and provided contextual meaning as to why individuals found themselves being considered for liver resection, there was no sense in that individuals were 'stuck' at the diagnosis and could not move forward from this point. Rather there was a desire to know what might be done and a desire to live, knowing fully that the alternative to doing nothing, would almost certainly hasten symptoms, decline in health and eventual death. Apart from the two patients who presented as emergencies, all patients were 'well'. As seen in 6.2.1, the shock of a reality that does not correspond with what one perceives about their health can be hard to comprehend but may also spur individuals on further to find solutions before their health declines. Patients voiced security in knowing that there was a plan early on, even if they did not know what that plan was.

The focus group was keen to hear the views of patients who had been through improvements to the pathway as they recognised that the perspective of the patient experience was missing from their discussion.

> *"I think it will be interesting to hear the patients' side of things as well, with the feedback and see where they perceive the gaps are" (Oncologist no.1)*

Clinicians operated from a position, knowing that what they perceived to be issues in the pathway may be different from those encountering it first- hand.

6.2.2.1 Looking forward to possibilities in medicine

There was recognition that until the standard treatment of liver resection was discussed by their health care team, that the majority of patients had not been familiar with this approach for secondary liver cancer. Only 2 patients had known indirectly through a friend of a similar situation where surgery was used as the optimum treatment for liver metastases, with others having stated similar sentiments as expressed by the following patient,

> *"I have never heard of this, I don't know anyone who has had this [colorectal liver resection] before." (Alex)*

Yet when 'up against it' with health, there is an anticipation borne in hope that in a country with an immense natural pride in the National Health Service, that something can be done. Combined with this is the knowledge that it is after all secondary cancer and therein lies a

tension about what can be done against the reality that cancer is a big force responsible for many deaths and has not been defeated. This may account for the growing picture that we see of many patients seeking alternative treatments elsewhere, many going to Europe or South America to pay for treatments have not been incorporated into the NHS cancer care due to lack of evidence (Gorski 2018). There is also a tension within individuals about the outcome of liver surgery, fluctuating between that of hesitant and hopeful of its success as Chris depicts in the following two quotations,

"I don't think there have been too many cases of people with secondary in the liver having had this operation and getting through." (Chris)

and

"I thought if this had been five or ten years before, it would be on the terminal list and so it's very important to get that across." *(Chris)*

Craig also echoed how much treatment overall for secondary bowel cancer had moved on,

"25 or 30 years ago they would never have had a cure for me like, no, definitely not." (Craig)

This gentleman's view was wrapped up in personal experience of family with bowel cancer when he could recount two cancer related deaths in the family.

Yet once presented with the possibility of surgery, the participants were clear in their understanding that getting to the surgery was the treatment that would prolong life. Therefore, achieving liver resection became the outcome or goal.

"The solution of surgery was a big, big issue for me. If it was just chemo, that would be a different perspective, but I felt that I had a chance with the surgery. I felt safe in the knowledge that surgery was what I had to try to get to." (Helen)

and

"In my head surgery equalled potentially getting rid of this, the best way to get rid of it, fully accepting that it could be back. I wasn't naïve enough to think that will be that but I thought if I can get to surgery that is my best option." (Julia, no op)

It was understood that historically surgery in this area was not used in this setting. This would have rendered a similar situation instantly palliative. Therefore, for these patients getting 'onto' the liver resection pathway became of sole importance. It was the only option for curative treatment. The oncologists at the focus group, confirmed that there were only a

small number who had a second and third liver resection once recurrence was detected following liver resection. The overall benefit of removing disease in those who recurred was not known.

> *""We don't know the answer to this…but for the patients that have surgery that aren't cured, has that still been a useful intervention in improving survival and improving quality of life by reducing the bulk of cancer?" (Oncologist no.1)*

The issue of quality of life could only be addressed through asking patients as to the perceived benefit of surgery despite potential or definite recurrence.

6.2.2.2 Acknowledging: 'There is no choice'

Having had the knowledge about what was potentially possible in liver resection, all participants wished to be considered for liver surgery. Having included participants who did not proceed to liver resection, it was important to ensure that the outcome did not colour what they thought of their experience in being considered. It was clear that participants did not feel that they had a choice. There was no alternative presented but equally participants did not refuse to be considered which could have been viewed equally as a choice. There was a sense of following it on to as far as they could go until the decision was made which in itself showed how much they wanted to live.

> *"I didn't have to make a decision, I didn't make a decision on that, there was no decision." (Amy)*

> *"I said go for it, one way or the other, I'm no gonna back out of it ken, I just went for it and that was that." (Craig)*

> *"Once I knew the road I was on, you know, there's no alternative, you know…it was do this and hopefully survive, or don't do this and you will be dead in three years' time." (Chris)*

An interesting point raised in the discussion was the use of risk data in helping patients look at the role of surgery, in the same way that data risk packages were used to help patients see the benefit of adjuvant therapies in the primary setting.

> *"Whether from our communication point of view we need to think about offering patients the numbers and you know if they know that for their pattern of disease there's an 80% chance of a recurrence despite surgery, would they still want to go down this aggressive pathway" (Oncologist no.1).*

This brings in an interesting element of what acceptable risk is. Presenting risk data is certainly a quite a different rationale to the patients' way of thinking in this sample, who all wanted the opportunity to pursue liver resection.

6.2.2.3 Treating with curative intent means an active wait

A key feature of being considered for CRLM, is waiting. Waiting is a notable feature in cancer delivery and has often received much negative press in the media related to targeted waiting times. Yet, a major part of waiting in this CRLM pathway is not a passive wait (unlike the comparison of liver transplant in Chapter 3) but an active wait and can involve a combination of treatments consisting of primary surgery/synchronous surgery, chemotherapy, and portal vein embolisation (PVE) to increase the capacity of liver resection as discussed in Chapter 3. In addition, radiotherapy may also be indicated in the treatment of rectal cancer which will then extend the workup to potential liver surgery should there be synchronous presentation of rectal cancer with liver metastases. In this sample, only one participant had short course radiation prior to primary surgery and in this case the liver metastases was detected during follow-up. The majority in this sample underwent neoadjuvant chemotherapy treatment prior to surgery (n=9). Chemotherapy was also utilised in two patient cases as adjuvant chemotherapy following primary surgery or synchronous resection and in one patient as palliative treatment when liver resection was not feasible. Only four did not have any chemotherapy as part of their overall treatment.

All nine patients undergoing neoadjuvant chemotherapy prior to liver resection spoke of the difficulty undergoing treatment. At the time of being treated a maximum of six cycles of CA-POX (capecitabine and oxaliplatin regime) was indicated. This commenced between 4-8 weeks following primary bowel surgery and is important to note that at this time patients were beginning to feel stronger from the bowel surgery. Starting cyotoxic treatment after going through major surgery and beginning to recover is often a reason why some decline adjuvant chemotherapy but in this case as seen in the previous section, patients do not feel they have a choice. The reality is that in wanting to get control of the cancer (ultimately seen as liver resection), patients are willing to 'sign up' to what the complete treatment may entail. This hits home, that in order to have the liver resection the majority of patients will have undergone two major surgeries and a chemotherapy regime (synchronous or metachronous presentation) unless a synchronous primary and liver resection is indicated.

Side effects during chemotherapy were a reminder of that long haul. Six out of nine patients who had chemotherapy prior to a liver resection, recounted difficult side effects that either led to a dose reduction or omitting a cycle of chemotherapy. Words or phrases used by participants to describe this period included, "horrific" (Chris) "couldn't handle it anymore" (Andrew), or "very tough" (Lynn). These are a reminder that quality of life was severely affected for these participants and suggest something of the bleakness of this period. It also acts as a powerful reminder of the lasting impact of this time, for some over a year later. Listening back and reading the transcripts brought this back as the participants recalled vivid memories about chemotherapy.

Common side effects included diarrhoea and peripheral neuropathy from oxaliplatin. Two people experienced ongoing problems with neuropathy over a year later. Alex encountered chest pain while on capecitabine and required admission and then conversion to 5FU by way of a Hickman line. Lynn had difficulty with low platelets caused by oxaliplatin which twice delayed her chemotherapy. Looking back about this period she said,

"It was a time where I lost control of my body. I was doing what someone else told me to do." (Lynn).

This feeling of being particularly low in mood and having to fight against the negativity of symptoms was common the further individuals got through their treatment regime. In particular, mid-way through the regime was when these feelings of negativity were heightened. One participant spoke of this when she said,

"I got to mid-way and I was crying all the time, which wasn't like me at all. I couldn't bear the thought of having more. I couldn't stop crying." (Jennifer).

Yet despite these side effects all participants carried on unless clinically told to stop. At the time of treatment eight cycles of chemotherapy (CAPOX) was indicated as adjuvant post-op chemotherapy. It is only with the results of the SCOT (Short Course Oncology Therapy) trial (Iveson et al 2018) that for the majority of patients, four cycles of CAPOX (three months) are deemed to have comparable disease free survival outcomes while having the benefit of a significant reduction in peripheral neuropathy. What did surprise me somewhat was the significant level of side effects experienced by 66% of this group. We cannot assume as health professionals that better tolerated regimes almost negate any side effects.

The meaning that individuals attached to continuing on chemotherapy helped to see why individuals carried on.

"The chemotherapy punched the cancer. It was worth it." (Richard)

and

"The chemo was doing what we wanted." (Robert)

Richard's description of the chemotherapy giving cancer a punch is reflective of the fighting language that is often used around cancer, some of which is often not helpfully received by patients (Hauser & Schwarz 2019). The second spoke of the desire of both himself and the medical team in seeing visually on imaging that the chemo was working. This meant that this time served a purposeful wait. Engaging in chemotherapy was an active wait. It meant that the time spent and the side effects experienced did not serve as a redundant wait.

The indication for lack of chemotherapy prior to resection could be viewed as negative as Helen revealed when she did not have it prior to resection number two. Having had liver metastases diagnosed during follow-up, Helen had adjuvant chemotherapy following primary bowel surgery and then at just a year was diagnosed with her first liver metastases. When it came to the planning the second liver resection, she was told she did not need chemo. In her mind, she had equated the chemotherapy to making the surgery more feasible and she spoke about how it played in on her mind, in addition to other concerns which are outlined in the horizon section.

"I couldn't understand why no chemo before the second liver resection. I knew there weren't as many tumours to shrink but isn't this the thing to keep tumours at bay?" (Helen)

This shows the interplay between knowledge from a patient's perspective and the medical team. Having had a comparison liver resection before, this patient was relying on foreknowledge to aid her understanding, much like the explanation of tradition that Gadamer speaks of (Gadamer 2013). Indeed, going deeper, it also hints at issues of strength of evidence for treatment in that as outlined in Chapter 3, there is a lack of hard evidence for sequencing of events in this area. This might to some degree be expected in a recently expanding area of medical experience but the challenges remain as to how such issues are communicated and heard by the patient behind the treatment. There may be a tension

between what the clinician knows as to the rationale for treatment or lack of it and what the patient understands. This brings in the idea of the 'professional' patient, who may be researching their own treatment but may be lacking in the context of decision making (Briggs 2016).

What I found most intriguing and resonated with my experience and challenge of communication in this area was how chemotherapy was viewed when a liver resection was no longer feasible. Julia expressed this, showing how she struggled with conceptualising the reason for neo-adjuvant chemotherapy. On reflection, for this participant, having the chemotherapy prior to liver resection seemed to indicate a delay and on hindsight, she may have been able to achieve liver resection had she forgone chemotherapy. If there is difficulty rationalising this process, it may be difficult for an individual to rectify why they could not proceed to liver resection without chemotherapy.

Three of the participants also required portal vein emobolisation (PVE) as discussed in Chapter 3, required with the intention of rendering the liver operable by leaving sufficient liver remnant. None of the three patients had been prepared that this may be required and having had PVE meant that liver surgery was performed 2-4 months after the patient had expected. What was apparent was that after further imaging (often PET or MRI) when the patient thought that the next step was chemotherapy, PVE was indicated. At such a time, when expectancy was high and the patient thought they had got over one hurdle, they found that this was an unexpected hurdle as the following quotations show.

> "There was a delay in getting it sorted out as to whether they could cut the three tumours out due to their location. They would have needed to cut out 84% of liver and you can't survive with 16, so they said, don't worry, we'll go to Plan B and do a liver embolisation." (Chris)

Chris went on to say,

> *"I had been gearing my mind up to get the operation in January and then there was that complication so the embolisation only went ahead in January or February time. Fortunately it was successful." (Chris)*

Further insight on learning of PVE is also seen in the words of the following patients,

> *"I was told they would have to do PVE. They did explain why. I thought I would get the liver operation in January but the PVE was done in January. This meant the liver operation was rescheduled for May but I*

had to have a few more weeks of delay because I had a UTI (urinary tract infection." (Andrew)

and

"My oncologist who told me that the liver surgery was going ahead but before we could go on, we needed to be sure there was enough liver left. I was a bit worried, I had never heard of this PVE before. One spot in the liver was 15cm and was very near to the part they were to leave." (Jennifer)

While all three embolisations were successful, clearly on reflection, at the time requiring a PVE caused some alarm and anxiety, mainly because it pushed the date of the liver resection further away than anticipated and added a further layer of uncertainty. Not having any anticipation that it might be required nor the added months for the liver to increase in size, made it harder to visualise the certainty of the pathway in their minds. In addition, the mention of the urinary tract infection, is a reminder of the fragility of health, in that other health conditions, be it resolvable, can jeopardise the liver resection. This reveals that good health in addition with successful neoadjuvant chemotherapy plus or minus other procedures have to line up with getting to a liver resection. Anticipation is a way of keeping options alive. This anticipation of working down routes in a pathway, is shown by Chris when he offers,

"I asked lots of questions about the treatment and liver embolization, but I didn't ask what if it doesn't work." (Chris).

Feasibility of a synchronous liver resection was also noted by the focus group to make a more problematic pathway for patients.

"It can be quite nerve racking I think, patients waiting for a synchronous resection because you have to co-ordinate liver surgical colleagues in the same theatre at the same time and that can be quite difficult. That can cause a further wait and of course the patient is thinking my cancer is still growing (Oncologist no.2)

This was certainly the view of Lynn who struggled with decisions off centre stage between her colorectal and hepatobiliary surgeon. On reflection she realised that it took time to co-ordinate theatre time but patients could benefit from some idea of timeframe for decisions to be made rather than having each week go past without a concrete update.

6.3 The companion of uncertainty: a unified horizon

Merging the data from the focus group and participant interviews revealed a second major theme in the CRLM pathway as that which I have entitled, 'the companion of uncertainty'. There was the sense that this was constant, a travelling companion that had to be learned to be lived with and accommodated as part of life. The combining of the perspectives of both participants and health professionals made me arrive at the conclusion that this theme could be seen as an overwhelming unified horizon from both participant groups. This was a first-hand experience for the participants and an observation of experience for the health professionals in which they recognised the ongoing struggle which permeated this pathway for individuals being considered for CRLM. Experiencing and observing meant that uncertainty almost took on a personified role. It became a sojourner, having no fixed resting place in the pathway but moving and transferring itself to a different form of itself when a different situation or obstacle was encountered during the process of being considered for CRLM. Uncertainty presented itself at the onset of diagnosis, not only of CRLM but notably of the primary tumour itself as was evidenced in section *6.2.1.2 Confronting a doubly shocking diagnosis.* At this stage it had become less fluid and something more tangible moving on from what was described in section *6.2.1.1 Transitioning the diagnosis: from the well to the not so well.* From the diagnosis, uncertainty became a recurring feature as expectedly individuals hoped for possibilities of treatment *(section 6.2.2.1 Looking forward to possibilities in medicine)* being mindful that without surgery by way of liver resection, there was no choice that would either provide cure or provide the best chance of extending life (*section 6.2.2.2 Acknowledging: 'There is no choice').* Options and sequences of treatment were explored involving imaging, and for many chemotherapy or for a small number PVE. Such treatment and phenomena experienced were presented in section 6.2.2.3 whereby it was seen that waiting was an active process undergoing treatment as part of consideration for liver resection. During this time uncertainty bubbled as a constant undercurrent with some situations, notably repeat imaging and complications of chemotherapy, giving more cause for hope or doubt that the pathway to liver resection was still secure.

Perhaps the reason for this constant companion of uncertainty is not just the obvious nature of the biological unpredictability of the presence of cancer but also the context of the pathway itself. The context of the pathway is not something always fully recognised by patients themselves, perhaps until they are further through the pathway or have had

opportunity to reflect upon it. After all, patients are the one going through the experience while the health professionals benefit from having a wider angled lens of knowledge of the difficulties of the pathway from encountering different situations from previous patients and seeing the whole and not just the part. The context of uncertainty is seen in the light of a pathway in transition.

Discussion in the focus group highlighted something of the evolving nature of this CRLM pathway, a reality which echoes that of the developments in the management of this area as referred to in Chapter 2.

> *"There are not many situations where, you know, aggressive management of metastatic disease can lead to long term disease control, it's not unique but it's an unusual situation in oncology." (Oncologist 1)*

and

> *"In the last few years the pathway itself has changed quite dramatically as well in the number of patients that are having liver surgery." (Colorectal CNS)*

The progress made in this area was also noted as a personal motivating factor for having a specific interest in this aspect of bowel cancer management with two health professionals expressing this. The transition of the pathway is part of the appeal which drives learning, new ways of working and better outcomes for patients.

> *"The area is interesting from the point of view of the number of different strategies you can use to try and achieve complete resection of the liver metastases, that is interesting." (HPB surgeon)*

and

> *"This is exciting from the point of view of more aggressive surgery which we hope translates into more patients remaining disease free long term but certainly more challenging as well in terms of patients having more and more radical procedures which for some of them have less chance of getting to that point of being cancer free." (Oncologist no.1)*

The later quotation highlights some of the challenges of more aggressive surgery and treatment, uncovering that while medical advancements bring much positivity and hope, they also throw up additional challenges, as outlined in Chapter 3 and cross referenced as comparable to that of many of the uncertainties faced when waiting for liver transplant.

While the pathway has evolved over recent years, there was also recognition that the pathway was one of personal transition and evolution for patients being considered for CRLM. Certainly, the language used by health professionals to refer to the pathway or pathway events, such as 'route', 'grind', 'long haul' and 'traps encountered' suggested that the health professionals were very aware of the personal time commitment to this pathway and that events could change the course intended. This is further accentuated in that the patient group being considered for CRLM resection could not be identified as a homogenous group but were a *"diverse patient group" (Oncologist no.1)* and that this in itself presented certain challenges.

Understanding the diversity of the patient group, meant that uncertainty for patients was also encountered in the challenge of management. The difficulty of defining liver resectability prior to an operation was evident in the literature and discussed in Chapter 3. With this in mind, the issue of patient selection becomes crucial but determining resectability and successful patient outcome, is not always straightforward and requires a multidisciplinary approach to management.

> *"The big challenge from my point of view is trying to define for a new patient, is this someone that has a realistic chance of being cured or remaining disease free with liver surgery or is this someone where biologically the disease is behaving in a manner where you think…that intervening with aggressive surgery for one site of the disease is not going to be of benefit" (Oncologist 1)*

and

> *"What guides my decision making is which is going to be the site that will mean that we can attempt treatment with curative intent, if we delay it…if the site doesn't make a difference, then your decision is down to whether it is technically possible or sensible to do a simultaneous resection" (HPB surgeon)*

The health professional possesses a clinical vantage from which to assess resectability. It might be difficult to present some of the clinical realities of the individual's disease to the individual for fear of destroying hope when undergoing treatment. Certainly, the emotional experience in caring for patients, particularly at senior or consultant level is an understudied area, as Orri et al's (2015) qualitative study with surgeons suggests. This may be closely related to the concept of infallibility as expounded by Gwande (2007), which he suggests has been compounded by traditional medical training.

In addition, due to the nature of surgical work-up, this process is often timely and has to be conducted in with the constraints of other workload commitments. Getting patients through whichever management deemed suitable for them in a timely fashion was also seen to present a management challenge.

"It is a multi-stage process and each of those stages does incur time and that really, when you add it all up, it can be several months from diagnosis of a colorectal cancer metastases to resection" (HPB surgeon)

and

"You do have to think about a number of different ways of achieving it, (resectability) be it with chemotherapy, be it with portal vein embolisation, be it staged" (HPB surgeon)

The pathway can be onerous in terms of time because of the complexity of decision making involved at different stages. Even once someone is deemed resectable after imaging and often following treatment, there are surgical considerations which can add time to the process of going ahead with a liver resection. This factor of time adds an additional worry to the patient as seen in section 6.3, the knowledge that metastatic cancer can be removed but that albeit necessary considerations add in delay. Lynn spoke of the perceived delay when being considered for synchronous surgery. In the end, she had primary resection and liver resection however she remembers feeling,

"Suddenly here I am with bits in my liver and the potential to have it everywhere and I don't have a plan for any surgical dates." (Lynn)

However, perhaps because there is no 'one size fits all' treatment, that responding to different tumour presentations and disease patterns, can add in further elements of uncertainty to the management picture.

"Patients are so individual and because management can be complicated, things can change" (Oncologist no.1)

The context of the liver resection pathway is one of transition which responds to people individually therefore emphasising the need for personalised medicine. This feeds into the uncertainty of management and in turn can create uncertainty for patients. It is hard to escape this uncertainty. The picture is that it is something to be lived with, a companion that is staying for the whole journey but a companion that could too easily get 'out of hand' and take over in an unhelpful way. It would appear helpful that measures to contain this companion of uncertainty would be employed. Certainly, due to the inexact science of

management for this group, the nature of change is something which can be an expected feature of the pathway. Perhaps the only thing that is certain is uncertainty in this pathway. Clinicians in this pathway were not only aware of the clinical management challenges but what is evident from the data is that as a by-product, their role also became about managing patient uncertainty.

6.3.1 Health professionals: guardians of the CRLM pathway

William Osler, when writing at the turn of the last century reputably stated that

> *"Medicine is a science of uncertainty and an art of probability." (Osler as cited by Taylor, 2011)*

While this could be true of many a medical situation, it is certainly apt of the pathway of CRLM. Determining the probability of CRLM is an ever evolving art, grappling with the constancy of uncertainty. Health professionals do not hold this uncertainty amongst themselves but have to communicate it to patients working between the interface of what is probable and what is realistic. In this the way uncertainty becomes a common feature to each and something of a unified horizon to view things from in a way to gain more knowledge about features or treatment of the pathway and an ultimate bid to gain more certain ground of what was going to happen. They were seen as guardians of the route to CRLM once that was something that was considered feasible. In this way connecting with health professionals was a way of connecting with hope.

Hope in this context had a certain phenotype. It looked like the plan. Undoubtedly the most important aspect of connecting with health professionals throughout the pathway was the maintenance of a plan. In this way hope towards liver resection was maintained. Identification of a plan early on following diagnosis of a liver metastases, was key in keeping the option for liver surgery open and also in determining trust and subsequent safety in the hands of the health professionals. A plan was a powerful tool, keeping a balance of emotions in check that either nothing could be done or that there was not some lurking awareness that uncertainty was ever present and a liver resection might not provide ultimate eradication of disease.

> *"Ms X, (colorectal surgeon) was positive that she had removed as far as she knew everything and that there were secondaries on the liver but that something would be able to be done about that as well." (Andrew)*

and

"They (liver team) said well I think we can operate on this and that was left at that stage." (Chris)

All health professionals were seen as important in imparting the plan although notably colorectal and liver surgeons saw their roles with differing levels of intervention and function.

"I think our role is probably more defined than yours because we tend to obviously be at the initial diagnosis and we tend to deal with almost our side of the problem…or we will be assisting them further in getting other specialists involved" (Colorectal surgeon)

and

"If I can't do an operation then it goes back to oncology" (HPB surgeon)

Helen reported not having a plan when her second liver metastases was found after her first liver resection. She remembers when she saw the oncologist she thought she would learn if further resection was at least a possibility. In the end it was, but she felt abandoned, recounting,

"Instead of saying we will see what the liver surgeons say, she said, now is the time to go and do what you want to do. I thought, hang on, that's not a plan. That's not a good perspective." (Helen)

It was this communication difficulty, later expanded on in 6.3.2.1 that Helen admitted to struggling with for some time with a negative impact on her mental wellbeing.

The colorectal surgeon tended to see the majority of those who had a synchronous diagnosis of liver and bowel primary and from there it was important to outline a plan, primarily through the mechanism of the multidisciplinary meeting (MDM). The hepatobiliary involvement centred on the feasibility of liver surgery but the role here did not encompass delivering a plan if liver resection was not feasible. The MDM was seen as crucial in bridging the gaps between three specialities of which two were in different teaching hospital locations.

Discussion at the health professional focus group noted that alternative health professional perspectives could be revealed, if the study was conducted in a different region of Scotland. This was considered to be due to the variation in approach to the management of CRLM on a national level.

"You should go across, you should go to the West of Scotland and repeat the exercise, because it's very much a regional, and there is so much regional variation in Scotland, it would be really interesting." (HPB surgeon).

and

"I think we are fortunate here we are very joined up, and certainly my impression from sitting in on a Tuesday, is that the liver MDM is much more targeted towards cancer. We are very fortunate we do have the liver surgeons coming here as well" (Oncologist 2).

The presence of the liver surgeons coming to the colorectal MDM to view scans was seen to reduce time between decision making, and was central in providing a plan at any stage of presentation or post chemo review for downstaging or neoadjuvant treatments. The consensus was that this area was fortunate to have the MDM in operating as it did and that that in turn eased management uncertainty for health professionals and in turn overall uncertainty for patients.

While overall health professionals were seen as guardians of the pathway, communicating specific insider knowledge within the context of the patient's specific case, oncology had a central gatekeeper role, co-ordinating decision making with input required from surgery as and when needed.

6.3.1.1 Oncology: a place of safe keeping

What emerged from the data was that for many patients being considered for CRLM, oncology represented a place of safe keeping while being considered for liver resection. This may not be surprising given that 75% (n=12) of this sample encountered oncology as part of their overall treatment with 62.5% (n=10) having known their oncologist when undergoing neo-adjuvant or adjuvant chemotherapy. For this reason, many of patients had built up a relationship during a review period with their oncologist with one referring to their oncologist as "the follow-up and maintenance man" (Chris). Given that the hepatobiliary surgeon and colorectal surgeon alluded to having a different depth of role with the patient in section 6.3.1. Then again it is not surprising that the feeling was one of ease with their oncologist as exemplified in the following,

"I think X (oncology consultant) is one of these people that can sit and talk to you and explain things in basically layman's terms as I would call them and make it more understandable." (Andrew)

There was almost a sense of homeliness and being comfortable in oncology because of the relational aspect that had been built up over time. It provided a safe place where hopes and fears could be understood in a commonality of understanding. There was also a knowledge that the oncologists worked closely with the liver surgeons so they were able to impart a plan for likelihood of surgery.

"Dr X (oncologist) was quite clear on the course of action, consult with the liver team first as it was felt the surgery was the solution." (Helen).

Being in a period of review allowed patients to understand how both liver and colorectal MDMs worked so that when the liver surgeon was not present at the MDM this had an impact on timely decision making.

"The oncologists and liver surgeons often have a meeting to discuss diagnosis and decision making. It would be beneficial to have them both together at the same time so that there is no back and forward situation. It doesn't have to be face to face but a conference call to avoid veering between the two and waits between the outcome of different meetings." (Helen)

Interestingly what we assumed might present a challenge in patients not seeing a liver surgeon until after imaging following treatment was not. The fact that patients did not seem to mind not seeing the liver surgeon early on near the diagnosis of liver metastases or at interim imaging suggested that patients felt held or safe in oncology, in the knowledge that their case was under discussion at relevant timepoints with the hepatobiliary team.

While the feeling was one of safety of management from patients, it was clear that trying to maintain this safety was a huge communication challenge. The issue of tempering information by realistic eventualities was highlighted by the oncologists present at the focus group.

"The big difficulty in communicating to patients is, you know in one sense you are trying to communicate that yes we are trying to get you to a position where you are cancer free with a chance of remaining cancer free long term but that has to be tempered with some realism." (Oncologist no.1)

and

"Although it sounds very easy, bowel cancer, liver mets, we'll remove that, all sounds very straightforward but actually the reality is an awful lot can happen during that time and communicating that uncertainty and the reasons for waits and the scans as x indicated is quite challenging" (Oncologist no.2)

It was noted that often issues were communicated when problems arose, rather than labelling out everything that could go wrong along the pathway.

"It's not so easy to temper (communication) with the 100 things that could go wrong during that process and it's often you just tackle those problems when they arise rather, than warning patients" (Oncologist no.1)

and

"If things go well in terms that they get through everything unscathed then that's very satisfying, but its preparing patients for the eventuality that this doesn't happen" (Oncologist no.1)

Marrying up pathway expectations of health professionals with a patient's expectations, can be seen to be something of a skill and an art. Several factors can interplay to make this difficult. The first may be differing expectations of timeframes. Since 2011, The Scottish Government have made clear a 62 day wait from referral of suspected cancer to treatment of a cancer primary (ISD Scotland 2019). For someone with CRLM cancer who has been told that surgery is the only treatment of optimum choice with the best outcome, it instantly starts the idea of the clock ticking. This can be challenging to try and reduce anxiety around this time when the professionals treating the cancer have other insight into outcomes which are not only based around time.

"Whereas I might understand that things take time, the general public perception is that if you have got a cancer, that unless you have it out within two weeks, it's a bad prognosis". (HPB surgeon)

and

"I try to explain the rationale…what I try and tell people, what I try to explain to people is, it is treatment done at an appropriate time, not treatment done now" (HPB surgeon)

This plays into the fact that it can often be knowledge about disease features that can affect expectations. The health professional may have a more nuanced understanding of the biological features and overall picture of a patient's liver metastases, which may affect how straightforward their pathway may be and could be used to prepare patients as to what to

expect. Understanding the cancer secondary at cellular level is important but as yet there are not the tools to adequately predict which patients will recur after a resection as highlighted by the following.

> *"Yes, technically this may be resectable, but biologically is this a disease where surgery is actually going to make a big difference? (Oncologist no.1)*

Such cases may represent patients where disease recurs in a short period after surgery and are more likely to be part of the continuum that are towards the palliative end of the spectrum. Yet, the on the other side of this is the unexpected expectation that the pathway can yield and that is when treatment advances bring about a surprising result and open up surgery as an option. This has occurred with the use of downstaging chemotherapy with Cetuximab (monoclonal antibody) for those that are KRAS wildtype.

> *"Until then we may be talking about disease control but at no point have we discussed you might get to a point where we will be talking about further surgery but there is always an obligation that things have gone so well that actually you have you opened up a door that wasn't likely to be opened." (Oncologist no.1)*

This possibility whilst infrequent, again highlights the pushing of treatment boundaries. The oncology team are central to managing these scenarios since they maintain the review of such patients and thus a place of safety of care is also recognised for these patients also.

Finally, difficult time-points in disease assessment were seen to play into the expectations of the pathway. The end of neoadjuvant chemo, following scans and completing chemo after liver surgery as the following quotations relate to;

> *"The end of pre-liver surgery chemotherapy scan, because is it or isn't it going to happen and some patients even get the length of going to theatre and you suddenly discover that there is a lot more disease than you expect. I've had a couple of patients in that situation and it's been just awful for them" (Oncologist no.2).*

> *"We've imaged them as best we can but still sometimes we get an unpleasant surprise and that can be devastating for patients" (oncologist no.2)*

> *"Getting them through that last part of the pathway is difficult and the evidence for incorporating that bit of the pathway is not really there, so you know I think that's tough." (Oncologist no.1)*

Notably, the oncology team are mindful of how friable the pathway is because of the nature of disease and how demanding the pathway is. Yet, perhaps because of this, there is knowledge for patients that there is a security in oncology taking on a role of key communicator between the liver surgeon. Interestingly, no patients from this group had spoken about wishing to see the liver surgeon earlier in their workup to a liver resection and were content that the liver surgeons were "*waiting in the wings*" (Laura) to review scans and provide opinions until they were ready after a period of treatment to meet. This itself suggests, that oncology was well suited as a place for care to be managed. Patients also went back to oncology for further follow-up after their post-operative liver review and felt satisfied for that to be the right place for continuous review. Patients who did not, went back to surgical follow-up under the colorectal surgeons for review following liver resection. While this may be adequate, questions might arise if this is the best place for long term review and detection of recurrence in the demands of busy surgical system. It might be that if patients could not be followed up in oncology, a nurse-led model of follow-up might drive a more protocol driven and timely model of follow-up (Al Chalabi et al 2011).

6.3.1.2 Nurse specialists: a welcome companion

Several colorectal guidelines endorse contact with a nurse specialist for the trajectory of an individual's cancer illness (SIGN 2011, NICE 2020). This was also the case in earlier guidelines which were applicable when patients in Phase 1 were having treatment. It is reassuring to know that all patients in both Phases had contact with a nurse specialist and in some cases and four in Phase 1 had also had contact with a hepatobiliary colorectal nurse specialist. The overwhelming message was that the nurse specialist was hugely valued across the treatment pathway, being seen as someone who travelled alongside the highs and lows from diagnosis to current care. They were seen as one who travelled with them on their journey, a travelling companion but with a different experience of the journey. Their role and input was welcomed, bringing professional insider experience with the added benefit of knowing the pathway. From the focus group, the Colorectal CNS present saw one of their main roles as managing patient expectation across that pathway.

> *"It's so important that patients still are maintaining hope along the way but it's how you temper that with realism" (Colorectal CNS)*

Here the CNS views their role in having responsibility to balance out what is possible in the pathway with realism in order that a realistic hope may be maintained. It was acknowledged that getting the same message across about treatment aims and possibilities was at times difficult but not only was the MDM important in this but the CNS was also important in blending the views of the whole team to maintain realism.

> *"a colorectal surgeon may be biased towards one viewpoint…a nurse specialist might be tempered with a bit more bringing them back and the oncologists and liver surgeons may have another different spin on exactly the same clinical situation" (Oncologist no.1)*

and

> *"MDM is a starting point but I think it comes from communication about this is what we're doing and actually seeing patients together…we often have a nurse specialist in and we are agreed on this is the message we are transmitting. It is very much managing expectations". (Oncologist no.2)*

Discussion amongst other health professionals recognised the role of the CNS had to play in helping to manage patients with metastatic disease. There was also an appreciation that the CNS role had evolved differently in Hepatobiliary than Colorectal and that more resources could be placed in nurse specialists, especially in the hepatobiliary unit.

> *"We would value the role of clinical nurse specialists across all our patches. The workload is too great for one." (HPB surgeon)*

> *"We are not geared up for cancer as such, so we see patients in out patient clinics, which is a general out patient clinic… I think the facility that we manage out patients from is not the best and you realise that the more you look at the facilities that are available across at the other hospital." (HPB surgeon)*

> *"Patients are, do not get the same level of support, care, that is available for patients with the bigger cancers… be that colorectal primary, breast cancer, lung cancer." (HPB surgeon)*

From this, it could be seen that the contact level with colorectal and hepatobiliary nurse specialists was inconsistent across the hospital settings partly due to differences in attributed funding which meant that the role of the hepatobiliary CNS had evolved differently than that of the colorectal CNS and could therefore not proportion the same amount of time of contact to those with colorectal liver metastases in the midst of a workload primarily with primary hepatobiliary cancers. This may explain some of the feelings of gaps in care that prompted

the study whereby patients and relatives were contacting the colorectal CNS team by phone with queries related to progress and decision making outcomes for those being reviewed by the hepatobiliary team. In addition, it also alludes to the fact that as treatments emerge and become more frequent as an established treatment, then the associated level of supportive infrastructure is not always present where focus tends to naturally be resourced on existing service needs. The level of accessibility to the hepatobiliary CNS was on an ad hoc basis, available if there was time to see patients rather than a given that contact could be made.

"I did have a helpful chat with the liver co-ordinating nurse at the Royal. She came into Intensive Care to see me as I was kept there for a few days before moving straight to the ward." (Andrew)

and

"I hadn't seen X (liver CNS) during the first and second resections but she did see me before I was discharged after the third resection. I always knew and do know that if I have any queries I can field them to X (Colorectal CNS). All the nurses on the team would tell you if they did not know the answer and would get back to the appropriate person for you." (Helen)

Perhaps the fact that all patients had met a colorectal CNS at the onset and had built some relationship over time there was that understanding that they could be accessed throughout the duration of the treatment and follow-up as the above quotation suggests. The idea of accessibility and presence may become an important feature for patients in helping to manage uncertainty and allay fears. Time too becomes central in knowing that the CNS has that ability to deal with concerns adequately, otherwise the value of access may not be worthwhile or realised by patients or family members.

"X (Colorectal CNS) had told us that if we had any more questions to pop back and see her or phone her." (Chris)

"They (Colorectal CNS team) make you feel that you're the only person that they're talking about, that there is nobody else in their mind when they're talking about you and what you've had done." (Andrew)

"You don't feel as if you're on a conveyor belt, you don't get that feeling at all." (Wife of Andrew)

What emerged from the focus group was a consensus on how beneficial it would be to have a CNS take forward a metastatic caseload and work with patients who were being considered for surgical resection of CRLM.

"Having one person who was the colorectal metastatic nurse specialist or liver mets nurse specialist makes it slightly easier for us." (Oncologist no.1)

"A point of contact throughout the whole pathway." (Oncologist no.1)

"We've spoken about it for a while that we would like a metastatic nurse for these patients, someone to take that service forward and not just for the patients with liver disease but for others as well with secondary disease" (Colorectal CNS)

"Because of the unpredictability it emphasises the need to have a keyworker, a key person to be a constant in a system that by its definition is likely to knock them" (Oncologist no.1)

Unexpectedly, the positive nature of the CNS role was highlighted from both patients and colleagues but the lack of consistency within and across site working was something that perhaps did not make best use of the skill set of the CNS in order to more effectively provide a supportive network for this group of patients and their families.

6.3.2 Reliable information: a remedy for uncertainty

Good communication in any healthcare and cancer care setting has been well documented. With what has been revealed about the nature of the pathway so far, it would stand to reason that communication is the ingredient that helps to oil the wheels in a rapidly changing pathway. Perhaps what we are guilty of as health professionals is that in our ability to see things with a wider angle, we can see the overall pathway in clear distinct sections. We can split each part up with certain characteristics or processes that are peculiar to that specific phase. When individuals are being considered for CRLM, distinct phases and understanding of each are only more readily identified in hindsight and inviting participants to interview has given them the opportunity to reflect on not just the whole of their individual journey but also the parts that have made up the whole. Yet the glue to making that pathway flow from one phase or part to the other is communication which informs parts of the overall plan in a timely and relevant way. Such communication cements the pathway together and gives a feeling of solidness or security.

Identifying helpful communication early on was one of the features that patients highlighted as important in the overall process. This gave character to how they felt the process would go on and a resultant confidence.

"I think the tone the consultant sets at the first meeting is very, very, important, that's critical that they have at that stage some kind of plan, even if it's only a we're not sure about this but this is our intention and this is the route map that we want to go on" (Chris)

Here, communication tone is linked with a plan, suggesting that qualities of hope are kept alive.

There is a significant input of time on planning how to achieve resectability and the MDM was seen as a central forum for decision making. It was noted as a "complex interaction"(Colorectal surgeon) between members of the network and one that "doesn't work well if people don't communicate with each other" (Oncologist no.1) or "didn't feel confident to ask an opinion" (Oncologist no.2). The CNS team imparted some of the information from MDMs in order to convey and act on information in a timely manner. While it is easy to gloss over this as very much a factual process, the majority of conversations took place on the phone and does not necessarily mean that imparting such complex interactions are easy. It requires an advanced set of communication skills which require the CNS to be imparting such information over the phone.

The lack of specific information on the CRLM process was hard to find. Nine patients had accessed the internet at some stage in their pathway and the majority of individual's family had done so. It was hard to get relevant UK information and information that was also not bleak in outlook.

"The bulk of reading on the internet was American material." (Helen).

This was a sentiment that was also echoed by health professionals.

"There's lots of information, but sometimes it is buried in a lot of nonsense that is worrying or not relevant for patients." (HPB surgeon)

and

"I'm not aware of any or much good information in this specific area but in terms of literature specifically on this pathway, I'm not aware that the team use anything or there is anything easily accessible." (Oncologist no.1)

Information seemed to be given verbally rather than written or signposted to internet sites. The CNS team were seen as useful to access for specific information and those that did felt encouragement to get in touch, also highlighting that they pointed out also useful services that they or family members might want to get in touch with.

"And she also mentioned the Maggie's centre and Macmillan service" (wife of Andrew)

and

"The nurse in the Royal was brilliant as well for information" (Chris)

While patients revealed that they did not have information on CRLM pathway, only one thought that practical aspects of physical recovery were lacking.

"I would have liked more guidance on recovery from liver surgery, especially to do with resuming physical activity" (Chris)

It must be remembered that by and large as discussed in Chapter 3, this group of patients are deemed fit for surgical resection and information on resuming lifestyle activities may be particularly important. This participant was an active gym member and wanted to remain focused in attaining a good post-operative level of fitness.

Finally, eleven patients had expressed that they would be happy to talk with other patients and seven had willingly offered during the interview. The possibility of a patient buddy system arose from the discussion and while recognised it may be worthwhile for some, it was likely to be a very individual service. This is concept is taken up later in Chapter 7. There were also some concerns on how patients would be matched to existing patients having gone through a similar experience.

"I suspect there are some patients who will benefit from it (other patients who have had similar experience), I suspect there are some patients who will not benefit it from it, how you choose, it also depends, so again it is a yes and no, because I don't think there is a one size fits all" (HPB surgeon)

and

"It's difficult because every patient is quite different and their experiences are very different and their own cancer is very different but there may be some benefit" (Colorectal CNS)

6.3.2.1 Struggles of communication give way to fear

It can be seen how much disease management, uncertainty and communication are entangled and dependent on each other. What becomes important is helping patients to manage their expectations along that pathway. Without this artful management, uncertainty begins to rise and makes the communication process less stable.

"It's pretty difficult, you know, and sometimes it's managing their expectation but it's really difficult because you know it's a long haul and patients need to see a reason for that long haul… in some ways to be able to put up with the grind of going through that pathway" (Oncologist no.2)

and

"It is splitting it up into the stages for the patient as well, realistic stages as well which may be starting off with their primary, removing their primary and then leading them onto the next stage. It's about keeping the patient up to date with what is happening as well" (Colorectal CNS)

Health professionals recognised that there were several points where communicating that uncertainty were heightened for patients, first of all occurring at a diagnosis of a liver metastases and also throughout the pathway when imaging can upstage disease and change the whole scenario of resectability.

"I suspect that it's the time between being told that they have got metastatic disease or recurrent disease to knowing that we can undertake resection or not undertake resection, it's that period of doubt." (HPB surgeon)

and

"You can go from a very seemingly straightforward position to actually this is more complex, this is more advanced with an extra scan and the whole situation can transform for potential cure or radical treatment to very obviously palliative, I mean that's a very difficult transition" (Oncologist no.1)

and

"It is difficult for patients because they think they are on the cure route but there are so many traps along the way". (Oncologist no.2)

The interesting use of the word traps by the oncologist in the later quotation suggests the idea of trouble waiting to pounce unexpectedly by several means. Ordinarily, the word traps may suggest that something can be done to avoid them by relying on some degree of skill very much like Snyder's (2000) hope theory whereby hope was seen as the power to overcome obstacles by the capabilities of that individual. The reality is that there is no individual skill as to whether patients would have resectable disease. All of this relies on the biologics of the tumour.

"There are some in between patients where the decisions are quite difficult and if you've got multiple lesions in all segments then you are drifting towards the palliative end of that spectrum, but you can't be definitive about that and these are the ones that you have to leave some uncertainty" (Oncologist no.1)

In the above quotation, the oncologist highlights how personal knowledge of the disease process and the pathway might suggest that liver resection is an unlikely possibility but that hope needs to be kept alive until the hope of liver resection is ruled out. In addition, an individual's communication preference were also noted to play a factor in communicating uncertainty. For some people, it is difficult to look at the alternative route until it is no longer an option.

"If there is a chance of a cure…why bother engaging the brain on the alternatives until you categorically hear it can't be done and I think a lot of patients do just that, it's what they want to hear" (Oncologist no.1)

Conversely another surgeon felt that for some patients, the nature of disease meant that they knew that surgery might not happen.

"Their expectation is that they are already uncertain, they know it is difficult, they know it is awkward and that it might not happen." (HPB surgeon)

It may be that unspoken levels of knowing pass between health professional and patient but in such situations there is the error that patients have not correctly understood or their understanding has been blocked by ineffective, misplaced communication as the following quotation suggests from Helen who had three liver resections suggests.

"There was no plan. This spun me into a negative scenario. If they waited to see the outcome from the liver surgeons, I would have been ok, but they put into my head this negative seed of doubt and it never left." (Helen)

She then proceeded to describe how because of a different oncologist's communication style, the seed of doubt that she would not get to liver resection started to grow from this point. She encountered many dark days and pulled away from contact with her brother because she found his style of communication negative at the best of times and it was not what she could manage. She then was diagnosed a few weeks after this encounter with depression through an intervention symptom trial accessible at the oncology clinic (Walker et al 2009). Through here she had counselling and was started on an anti-depressant.

"The second liver resection was a different scenario to the first, it wasn't fully explained, I didn't see the same doctor I had seen before and there were multiple lesions on the liver. Then came the third scenario of the third recurrence. It was quite clear what they were going to do, cut it out, and chemo phase. The focus was different." (Helen)

Perhaps on the second occasion of liver recurrence, not having the trust relationship with the same oncologist unsettled this participant, combined with the different emphasis on communication style which somehow reduced the role of hope until the option was reviewed by the liver surgeons.

Another participant spoke of the emotional impact of learning that her case had not been discussed at the MDM as intended.

"My case had not been discussed at the meeting it was scheduled for, so that was another week, so there was a whole series of odd delays. It was very difficult. At this stage, a week's delay seems a significant time." (Julia, no op)

This shows that in a pathway where patients are often informed about when discussion will occur on an MDM, the anticipation of discussion has a significant impact on individuals, especially if that discussion does not result. It can also make it harder for those (often the nurse specialist) to contain information for those patients and provide necessary reassurance when sought after information is lacking.

6.3.2.2 Language has a memory

Closely connected with the appreciation that struggles of communication gave way to fear is the understanding that language held memories for patients which became hard to escape. Language use by health professionals can create powerful memories for patients which can hinder how individuals access hope during that pathway. This is often notably what is or isn't said.

Looking upon one example more closely, it can be seen how language spoken early on in the pathway, robbed hope and coloured how the effectiveness of treatment might be seen. This participant recounts remembering how on the morning of her elective bowel surgery, chatting with her surgeon before going to theatre. At the time she knew of her liver metastases diagnosis but was focusing on getting through her bowel surgery.

"I do remember on the morning of my surgery, which was about September by this time, and I still was feeling very well, he said to me something like, 'well you're a borderline case', but what does this mean?" (Julia, no op).

These words about being a 'borderline case' confused and jarred with her, especially while trying to focus on what was ahead of her and feeling already vulnerable just minutes away from the anaesthetic room.

"He didn't really explain but he did go onto say, you know if we do this surgery and then once we see how things are, the other surgery will depend because we won't operate if it's going to be futile, and that's the two words that I have carried on my head to this day, borderline and futile. It knocked me for six and I didn't tell anyone about it, not even my family. I thought I can't mention the word futile." (Julia, no op)

Here it is evident how much language sets the tone of what might come ahead. Not only was this participant unable to query the phrase verbally due to her compromised situation but the words suggest that she was also too stunned by the words of borderline and futile so much so that she kept it hidden from anyone. The opportunity for interview allowed some of this language angst to be voiced and the hidden to become transparent. Helpful language or conversely unhelpful language can have long lasting effect and colour other events along the pathway. Language can determine how others have the confidence to communicate to their family/friends about treatment. The interview itself may have allowed Julia to share the devastating impact of this language that she had carried with her, therefore assisting her to work through some of these issues. Nguyen et al (2108) were able to demonstrate that fear played a part in poor memory recall at a clinic for newly diagnose cancer patients that was independent of patient age. While it has been well documented that patient recall of medical information can be poor, what Helen recounted was a certainty over certain words and how they had impacted her. In accounts were language has been problematic it has not been the message but the use of certain adjectives or nouns that have been remembered. Dizon (2012) writes,

"While our colleagues may understand what we mean when we refer to treatment …the same may not be said of how our patients or the public hear it." (Dizon 2012, para.15)

6.3.2.3 Uncertainty: a forever friend

The findings have shown that uncertainty is something that is a feature of the whole pathway and is also apparent part of the whole by being apparent at specific stages of the pathway. Gaining knowledge of a specific part of pathway experience during an interview was in the context and flow of the whole pathway experience. Helen who had three liver resections also shows that a previous knowledge of the pathway does not make managing uncertainty any easier and can give a different feel to the overall pathway. This is why it has also been important to include patients who were not able to proceed to liver surgery and not achieve the outcome they had hoped as the focus became issues in the pathway irrespective of the outcome in hindsight. Not only is anxiety favourably managed by a plan as seen in section 6.3, it is also apparent that personal attributes and past experiences in life could cause individuals to react differently in similar situations as seen in section 6.4.

For those who had a liver resection, one notable time where uncertainty became apparent and 'reared its head' was in follow-up imaging. Both Lauren and Richard recounted how the process of having scans in follow-up caused significant disruption to their family life also, not being able to focus on normal life. Lauren recalled,

> *"I had just about learnt to put it out of my head wh*en another scan came up. I am beside myself at the time, waiting for the results. Were it not for *my partner, keeping my focus, I would not be able to function."*
> *(Lauren)*

At one point, Alex had talked about how he thought there was liver recurrence when a CT showed something suspicious. It was a further four weeks before he had a MRI and PET scan and had been informed after a MDM that the liver was clear. While his wife found this time very difficult to manage, Alex said that he managed to keep fairly calm, stating.

> *"I always knew th*ere were no guarantees. Nobody actually had said to me, that's it, your liver is cured." (Alex)

Perhaps the only thing that is certain in this pathway is uncertainty. It is clear that the changeable nature of the CRLM pathway can present additional challenges in managing patient anxiety and that health professionals in the team cannot eliminate this uncertainty. It will always be present during treatment, in follow-up and into survivorship. However, finding ways to manage expectation and reduce unnecessary uncertainty and anxiety become increasingly desirable for this patient group.

6.4 A journey of personal revelation: an individual horizon

> *"Science may provide the most useful way to organize empirical, reproducible data, but its power to do so is predicated on its inability to grasp the most central aspects of human life: hope, fear, love, hate, beauty, envy, honour, weakness, striving, suffering, virtue." (Kalanithi 2016, p. 170)*

The final super-ordinate theme relates to the personal learning which participants discovered through their experience, those which are more existential, touching on the value and purpose of life. Paul Kalanithi (2016), a trainee neurosurgeon wrote about the impact of stage IV lung cancer and the lessons it afforded. These were lessons that only he could declare. The same goes for individual learning through a cancer experience. As health professionals, we cannot declare any positives of an otherwise negative experience for patients. This remainder section will briefly touch upon some of the individual horizons shared by patients. Returning to this aptly describes how Gadamer explained that we apply our pre-understanding to interpret the present and in so do we complete the circle of understanding, for a time (Clark 2008).

The word journey in cancer, can have negative connotations for patients, (Semino et al 2017) mainly because a journey normally has an element of choice and is an enjoyable experience. Yet, Semino et al's (2017) mixed methods study showed that patients used the word online more than health professionals did and that it did not always have a negative connotation because there often were insights gained that they recognised would not have occurred had they not been on this route. It seemed relevant to use it in this theme because it was evident that patients had viewed it as such and often used words such as track, route, path. The interviews provided participants the opportunity to reflect upon a period of life where their health and indeed life itself was at risk. Four of these participants, who could not proceed to liver resection were known at the time of interview to be in a palliative situation but yet it was not clear who might develop recurrence from the participants who had been able to proceed to liver resection. The previous section highlighting the certainty of uncertainty in this situation is a reality, bearing in mind that the interviews only provided a snapshot in time of the then current situation. They could not point to any of the longevity of the results over time. Allowing the participants to cast their mind back to their diagnosis all the way through to their present situation in the context of having secondary spread to the liver has also yielded the participant's individual horizon from which to look at the overall process. In some

ways this showed the sense of meaning that they attached to this episode in their lives and also what afforded examples of personal learning throughout the process. This was in many ways an unintended pathway but one in which we may often not be party to as health professionals. This unintended route was a by product of the cancer diagnosis and would not have occurred had it not been for this diagnosis.

6.4.1 Unintended pathways

Two pathways that were particularly evident came as a result of being able to both reflect upon their experience and look towards the future. These have been entitled as 'learning looks forward and 'gratitude gives back'.

6.4.1.1 Learning looks forward

In addition to the support that the health professionals had afforded in previous sections, learning was identified as learning from others and learning lessons about self. On a number of occasions, people alluded to learning from other patients that they met through their experience. This may be a brief encounter or may take place as a more regular contact, such as being scheduled for chemotherapy on the same day.

Robert had spoken about how he had been in a hepatobiliary ward after his liver resection with patients who were awaiting liver transplant and had been alcoholics, seemingly having no control over their drinking habits. It had made him realise that although 'it was not a cheery place to recover', it did afford him the time to think that he could take a part in his recovery and future decisions. Julia also spoke about how she had been on a ward with some patients who had throat cancer and had found the symptoms of their cancer 'quite distressing at times'. Although Julia could not have liver resection, she had considered that her situation was not like theirs as she was able to enjoy, in her eyes, a much richer quality of life. Craig remembered meeting an older lady regularly in the chemotherapy unit, whose attitude to chemotherapy and life had inspired him and although he did not know anything of her cancer or circumstances, the encounter had been made him more determined to complete the chemotherapy and look at the positives in life.

There were additional lessons about self which were to do with adjustment of the process of illness. Helen had recounted how getting through a period of extreme depression was one of the toughest periods of her life.

> *"Just before the second liver resection and particularly after it, I went into a depression. …I couldn't see a solution other than death. Everyone else was planning holidays and years ahead and I could only see to the next blood test.". (Helen)*

Having got through that period and then underwent a third resection, she had explained that she had learnt a lot about how she coped with this darker time in her life. At the time of writing, Helen remains disease free but had realised that she could not always rely on planning her way out of situations in health that were beyond her control unlike other situations in life and work where she always had an element of control. Lynn also had realised how much she had moved on in her thinking from struggling with a previous alcohol dependency issue. She remembers a difficult wait when a decision was being made between the surgical and hepatobiliary surgeons as to the feasibility of a synchronous resection. The wait seemed to go on keeping Lynn in limbo as to any plan. She recalled,

> "I could have done with a drink." (Lynn)

What Lynn would have done to cope with this situation had changed but at the same time, the situation taxed Lynn so much that she was in danger of returning to destructive health habits. Due to the seriousness of her drinking, this in itself would have jeopardised her ability for resection.

In a similar vein, others had realised that having been through all the treatment and had a successful liver operation, that they were in better health.

> *"Emotionally and mentally I think I am quite happy where I am at the moment, I am fit and my energy levels are back to normal. I feel at my healthiest for years." (Amy)*

For others it was the sense of time that had been accentuated through the process and how they wanted to guard it for the future. For both Chris and Robert this meant cutting down on their time commitments to work to spend time with family. Robert had spoken about how it had made them reassess their time commitments to work. Robert had recollected,

"I could have been in South Africa and America in the same week. I realised I was hardly seeing my wife and family. It wasn't how I wanted to go on." (Robert)

The reaffirming of significant relationships was an important feature for several participants. Closely linked to this was a sense of appreciation for these people in their lives who had accompanied them. Participants saw that their significant others had no choice in accompanying them in this route either and wanted to frame the future differently. Knowing that there was a future to be had allowed participants to appreciate their journey. This was irrespective of achieving liver resection or not but was part in part of the instructing nature of cancer as Annis writes,

"And then cancer did the unexpected. She taught me how to find gratitude. Cancer is a good teacher. I can't say I like her, but I do appreciate her. I'm grateful for the valuable lessons she's taught and yes, I might have learned those lessons without her, but with her, I think I learned them a little better than most." (Annis 2018)

6.4.1.2 Gratitude gives back

The feature of gratitude was evident in the participant stories. Gratitude has the ability to look all the way back to the individual's original position, benefitting from perspective. This stemmed from the knowledge that liver resection was possible as explored in Section 6.1.2.1 in the context of treatment advances that made it possible. For Richard, this began before confirmation of diagnosis. After his liver resection, he wrote to the bowel screening centre, and giving a paraphrase of his letter he wrote,

"You saved my life, you are absolutely brilliant and without it I wouldn't be able to write this letter now." (Richard)

Richard also picked up on the sense of bewilderment when people whom he knew did not participate in bowel screening as for him it had saved his life. This made him determined to do some volunteer work to help promote screening.

Many of the participants had expressed a willingness to be contacted again to help with any further work or speak to others who were in a similar situation. This concept became one of the strands of the support model and is enlarged upon in Chapter 7. This was something entirely unprompted by myself as researcher at the time of the interview. It may have been

that through the interview, the reflection process, enabled feelings of gratitude, that were already present, came to the fore.

Additional feelings of gratitude related to personal circumstance were also evident. Three patients noted that they did not have dependants to consider in this process, having come in contact with people much younger who also had metastatic cancer. Others mentioned they did not have pressures of work to consider getting back to being now retired and three mentioned they were grateful they did not have monetary concerns. Robert remembers one of the chemotherapy nurses mentioning to another patient that a digital thermometer would be useful,

> *"It made me think, that's about twenty pounds. I mean if you were short of money or you were at work, I mean you couldn't work through this, the pressure on you would be heavy." (Robert)*

The ability to share in the humanity of another and enter the shoes of someone in a similar situation was apparent.

6.4.2 Arriving

At first glance, it may seem difficult to talk about 'arriving' when the evident uncertainty in the pathway to liver resection presents a fluidity that means one might 'arrive' to have a resection only to later have a recurrence or one might think they will have a resection only to find that they cannot. A helpful definition of 'arrive' in the context of this study is,

> *"To reach a place, at the end of a journey or a stage in a journey." (Oxford University Press, 2018, online, paragraph 2.)*

This definition helpfully encapsulates that it is not just the overall end of the journey that is important but the stages along the way. At the time of interview all participants were in no doubt as to what point in the journey they had arrived but were mindful of the uncertainty ahead. Having understood this, two further sub themes, 'What matters most' and 'Keeping hope alive' were identified.

6.4.2.1 What matters most

There was recognition that having had the diagnosis of secondary colorectal cancer and been on the pathway to liver resection, the preciousness of life was accentuated. This was evident in the appreciation of the small things of life as the following quotations suggest,

> *"I'm trying to life a normal life. I've found it difficult to meet some friends. I know that's a small thing, but it's the small things in life that make it worthwhile." (Robert)*

and

> *"I'm living each day as it comes. I've lots more living to do." (Julia, no op)*

These quotations support the popular adage, 'one day at a day at a time'. For the participants there appeared to be some genuinely life affirming moments where the importance of family, friends, a quiet moment, a sunset were realised as if in slow motion but what is not clear for many patients is, if disease is no longer containable, what does that mean in terms of time? Paul Kalinithi struggled with this very aspect when he wrote,

> *"The truth that you live one day at a time didn't help: What was I supposed to do with that day?" (Kalinithi 2016, p.161)*

Several patients alluded to the fact that while grateful for the treatment, cancer was in itself a huge inconvenience to the normality of life. Many participants appeared apologetic for mentioning social situations, family gatherings or holidays that they had missed because of the cancer treatment. The reality was that these things augmented and helped them continue, with Lynn saying,

> *"During treatment, I felt like I had given my body over* to someone else. I didn't have control over where it needed to go over the course of a year. Keeping up social interactions and travel after the resection was a way of getting that control back." (Lynn)

This highlights how important it is to work with individuals and their sense of priorities and yet may present some challenges in how we can accommodate flexibility in a busy healthcare environment. It also points to the fact that when liver resection is not feasible, perhaps we do have an obligation to help manage an expectation of time as Paul Kalinithi also alludes to. What patients might choose to do in that time might change depending on their knowledge of it.

6.4.2.2 Keeping hope alive

Hope was the common concept which rippled through the patient stories at diagnosis, at treatment, at point of decision making regarding resection and beyond. For all patients, regardless of liver resection, it became a way to define the future.

For many, vocal confirmation from the Hepatobiliary team about the status of the liver, allowed them to be confident to have a future,

> *"He (liver surgeon) sort of just said, it's all gone, away you go, go and get on with your life." (Amy)*

This was also reinforced by the oncology team when they confirmed that follow-up would remain with them and there was no further need to see a liver surgeon. At the same time, patients were aware that there may be other things the liver surgeons could do should a liver recurrence return. This relates back to Section 6.1.2.1 on believing in possibilities in medicine. Possibilities keep hope alive.

For others, it meant that their future could only be evident if other health needs were addressed. For Steven this meant taking measures to reduce the risk of stroke as his chemotherapy had been stopped due to likely cerebral vascular attack. For Alex this meant starting treatment for prostate cancer.

Others had mentioned feeling hugely saddened to learn of well known people who had died. Both Jennifer and Julia had mentioned the death of author Iain Banks leaving them more devastated than they expected. They had invested in his story with their own story running parallel.

Hope was evident in those who had not proceeded to liver resection while at the same time they were aware of the reality they faced. Tom had made clear,

> *"There are no miracle cures. I've tried everything. I've done everything but I'm on a trial now. Trials are there to help someone in the future and I might do that." (Tom, no op.)*

Both Paul and Julia found that receiving an explanation as to why treatment could not go ahead from the liver surgeon was important in moving them onto the next stage to allow them to consider other options. Having done that, Julia had been able to say that she was "looking towards the horizon of summer" to enjoy some things she had planned. This is an important aspect to consider and offer when so much time has been invested by the patient

in being considered for liver surgery. If the pathway comes to an abrupt halt, it may require some time to process the rationale for no surgery with the help of health professionals involved. Perhaps this ability to look back in order to look forward provides a realistic hope and is a more complex process akin to that of Oettingen's (2015) mental contrasting outlined in Chapter 4. As for Gadamer, people learn their limitations and restrictions by the presence of disease. There is no doubt, that the process of being considered for liver resection is particularly challenging, but as Gadamer would attest, it is only the real person who can enter and let us know the difference between health and disease (Šolcová 2008). Our position is to listen.

6.5 Hope in a complex pathway

The themes uncovered through Phase 1 data, can be condensed to central concepts of expectation, uncertainty and understanding. All of the particpants saw the goal of CRLM as something to be held up and attained. In essence, what they shared were stories of hope. Hope was the mechanism used throughout the pathway and expectation, uncertainty and understanding were components of that hope that flucuated and in turn affected hope. This can be see diagramatically in Figure 6.1. overleaf. There was an ebb and flow of hope that was responsive to situations encountered throughout the pathway. Connversly, these situations often altered an individual's view of hope. This links back to the philosophical underpinnings of hope as discussed in Chapter 4, whereby hope has had both positive and negative connotations. Understanding these components and how they can ultimately affect an individual's hope, has a bearing on how health professionals can work with patients to set expectations, manage uncertainty and check understanding throughout the CRLM pathway. This may also have applicablility to other complex cancer treatment pathways.

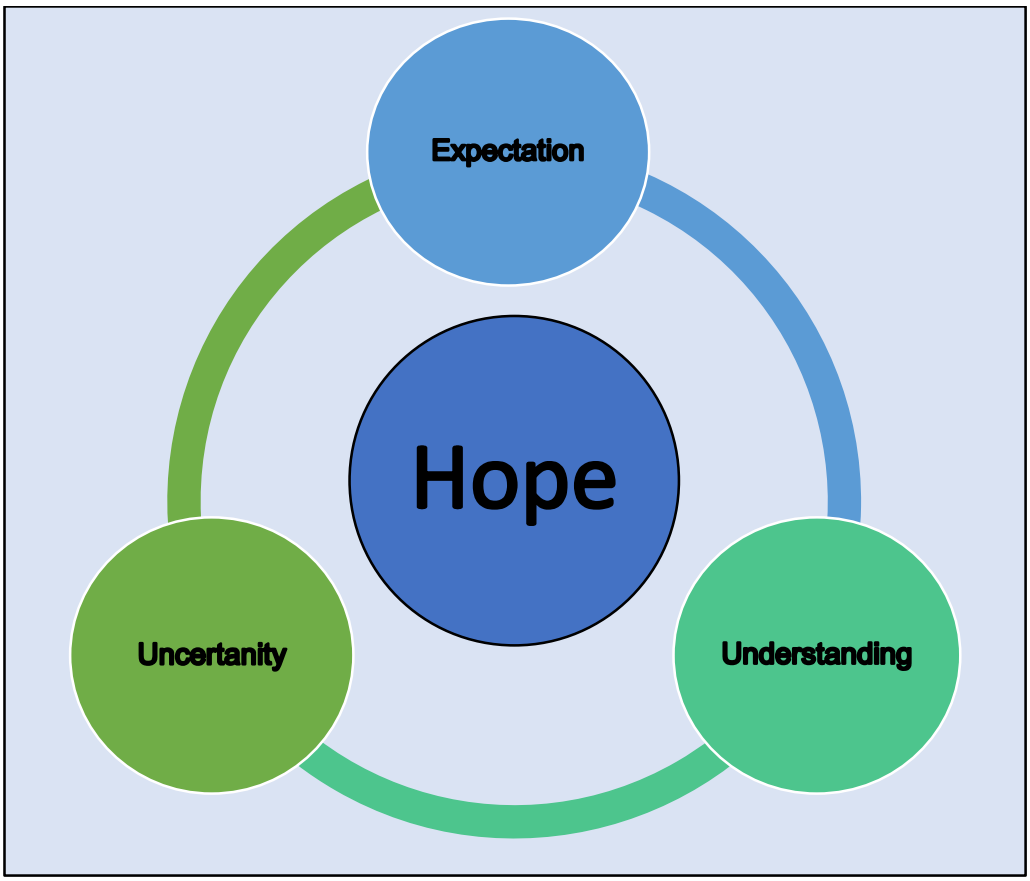


Figure 6.1: Components of hope operating through a complex pathway

6.6 Chapter summary

This chapter has presented that findings of the participant interviews merged with the health professional focus group in Phase 1. Uncertainty was evident throughout the pathway. Using Gadamer's fusion of horizons allowed to find meaning in the layers of data. Three horizons were formed which allowed to see that the process of understanding liver metastases was rooted in an individual's diagnosis, the oncology team were best placed to co-ordinate treatment related to liver resection and that overall these experiences were stories of hope. While uncertainty was a given throughout the pathway, maintaining hope provided an antidote to uncertainty during the pathway and beyond for individuals who proceeded to liver resection and did not. The findings then provided the basis for developing a model of support for this patient population which is discussed in the following chapter.

Chapter 7

Merging patient experience with revision of service delivery

"The improvement of understanding is for two ends: first, our own increase of knowledge; secondly, to enable us to deliver that knowledge to others." (Locke 1689 paragraph 405).

7.1 Chapter overview

Having presented the findings in Chapter 6, this chapter will explain the response taken to revise the current support pathway for those being considered for CRLM liver resection. It was the intention to marry the patient and health professionals experience of the CRLM pathway with a response that was both fitting to the data, appropriate to the patient population and matched existing nursing resources. What resulted was a support pathway of three parts, executed predominantly by the colorectal cancer nurse specialist team. This comprised of a telephone support model, development of patient literature for the CRLM pathway and formation of a patient buddy support service. This chapter will incorporate a reflexive approach that seeks to respond to the research findings as I firstly revisit the original intentions of the research study and then outline each strand of the overall support pathway.

There is a growing body of literature on the relevance of all three of these strands in cancer literature, (telephone support, patient information and peer support), yet while reference is given to some relevant literature, this chapter is not intended to spend time reviewing the current literature. The reason for this is clear. The approach adopted for the support pathway was in clear response to the analysis of the data in Phase 1. To remain true to the experiences of the patients interviewed and the perspectives of the health professionals in the focus group, the support pathway required to model these experiences rather than take its inference from existing literature. In addition, the approach used, should be conducive to the methodology of hermeneutic phenomenology in seeking to improve the experiences of patients being considered for CRLM. In this way, the study methodology supported the method of developing the intervention of support and similarly, the method applied, supported the methodology. What follows is not revision of the CRLM pathway itself but revision of the way nursing support was delivered to patients at the time. As Locke's (1689) quotation at the opening of this chapter suggests, the study was conducted as a nursing study in order to deliver new found knowledge to future patients who might benefit from it.

7.2 Revisiting intentions

From the start, this study encompassed the nature of the 'so what?' of the research question. Selwyn (2014) in an editorial, shares one of the key lessons learned during his doctoral studies and that was always to be mindful of the 'So What?' question. Selwyn recounts that this has significance both when publishing but also early in the research process of academia to reinforce to the researcher that the connections in their head as to why the research was conducted, require to be easily conveyed as relevant to their intended audience. This study was never intended purely to encompass an exploration of the patient's experience of the CRLM pathway and the views of health professionals without aiming to improve future patient experience. It was intended to build on what had already gone before by taking account of the merging horizons of patient and professionals experiences which in turn would allow for greater focus on this group of patients in order to help address needs during consideration of CRLM resection. At the same time, the outcome of the study was not pre-emptive of the data gathered in Phase 1 but was responsive to the findings, focusing on individual patient experience and the collective patient experience as set out in Chapter 6 and analysed with the use of IPA methodology. Importantly, as the data were analysed from Phase 1, it was also apparent that acknowledgment should be given to the context of an emerging treatment field and how revision of the service needed to be responsive and applicable to potential changes that might occur as treatment options emerged. Additionally, it was vital that any options were considered against what resources were in place to deliver the change and more importantly, in order to sustain any future change. The quotation above from John Locke, known as the father of liberalism (Hersey 2019), was relevant to the context of reading but aptly describes how gaining understanding or knowledge is of little value if it does not make its impact somewhere. It also highlights that change does not need to be hugely radical in order to make itself apparent and felt. Indeed, it may not always be obvious to others within the service but it ought to be experienced by those using it. It is this emphasis on putting the results into practice or translating them that has driven this study. Too often nurses rely on experiential knowledge, trial and error, and peer opinions for decision-making instead of research (Stokke et al 2014 as cited by Younas & Porr, 2019). Application to healthcare improvement ought to be evidence of using nursing research as the following quotation suggests.

"Knowledge translation (KT) emphasizes a shift in researchers' practice; that is, rather than merely publishing in journals, presenting at conferences, and shelving research reports in university repositories, researchers should strive for the research uptake and its actual application for the improvement of healthcare and patient outcomes."
(Younas & Porr 2019, p.924)

At this point it is worth reconsidering the original aims of the study. The aims were:

- ●To investigate how patients experience the pathway to liver resection
- ●To examine how health care professionals view the pathway to liver resection for patients
- ●To use the experiences of both patients and health care professionals to plan and implement a service improvement to the pathway with the addition of supportive nursing intervention.
- ●To explore whether additional nursing interventions during this pathway improves the experiences of patients being considered for surgical resection of liver metastases following service change.

This chapter deals with the third aim, implementing service improvement. It acts as a reflective pause between chapter 6 and chapter 8 to consider the results, seek to implement a response and then re-evaluate the service. The results discussed in Chapter 6 highlighted an existing service where many of the actual patient experiences were hidden from health professionals involved, yet at the same time the health professionals had the knowledge that the pathway to CRLM resection was complex and due to the nature of the disease itself had the potential to cause huge uncertainty. Chapter 6 has presented the findings merging both the patient interviews and health professional focus group. This was achieved under three main themes which incorporated a fusion of horizons including my interpretation of the data as someone who was unapologetically both researcher and insider. The three overarching main themes:

- a path of expectation: an enduring horizon
- the companion of uncertainty: a unified horizon
- a journey of personal understanding: an individual horizon

The themes comprised both super-ordinate and sub-ordinate themes as set out in Chapter 6 and also overleaf in Table 7.1 (although with differing number referencing in this chapter table). As with all phenomenological research, there are a number of ways to present or describe themes. I had arrived the above themes as I felt it had captured what was presented

in the raw data and reflected both the Gadamerian philosophy of fusing different viewpoints to arrive at a viewpoint which was aptly conveyed the input of health professionals involved in the pathway but also with the context of the insider/outsider position of myself as researcher.

Master theme	Super-ordinate themes	Sub-ordinate themes
1. A path of expectation: an enduring horizon	1.1 Travelling with the backdrop of diagnosis	1.1.1 Transitioning the diagnosis; from the well to the not so well 1.1.2 Confronting a doubly shocking diagnosis 1.1.3 Questioning in the context of 'me'
	1.2 Hoping for chances: desiring life, desiring time	1.2.1 Looking forward to possibilities in medicine 1.2.2. Acknowledging: There is no choice 1.2.3 Treating with curative intent means an active wait
2. The companion of uncertainty: a unified horizon	2.1 Health professionals: guardians of the CRLM pathway	2.1.1 Oncology; a place of safe keeping 2.1.2 Nurse specialists: a welcome companion
	2.2 Reliable information: a remedy for uncertainty	2.2.1 Struggles of communication give way to fear 2.2.2 Language has a memory 2.2.3 Uncertainty: a forever friend
3. A journey of personal understanding: an individual horizon	3.1 Unintended journeys	3.1.1Understanding looks forward 3.1.2 Gratitude gives back
	3.2 Arriving	3.2.1 What matters most 3.2.2 Keeping hope alive

Table 7.1: Themes revealed from Phase 1

Conveying the essence of the findings in order to implement a service change, however, can become more challenging in the context of the clinical setting. This to me, is where that 'so what?' question of research really comes to the fore. How can findings become embedded or useful in clinical practice if they are not well communicated? For me, the themes required to be re-communicated in order to capture easily the essence of what was already good about the service and what could be improved. This meant using workable phrases to understand the findings within the context of positive experiences and against more challenging experiences. These phrases were therefore simply divided into positive experiences and more challenging experiences for the purposes of practical communication and can be viewed in Table 7.2. The phrases have been shown to map to the themes listed in Table 7.1.

Colorectal Liver metastases pathway: a pathway of hope	
3 main components of hope permeated the pathway - **Expectation** - **Uncertainty** - **Understanding**	
Positive experiences	**More challenging experiences**
Sense of cohesion between teams regarding plan of care (2.1, 2.1.1, 2.1.2)	Uncertainty from changeable nature of pathway (1, 1.2, 2, 2.2, 2.2.1, 2.2.2, 2.2.3)
Sense of security in being anchored in oncology (2.1.1)	Managing a realistic hope (1, 1.1, 1.1.1, 1.2, 1.2.1, 1.2.2, 1.2.3, 2, 3.2.2)
Sense of gratitude to team (3.1, 3.1.2)	Lengthy co-ordination of decision-making/management (2.2.1)
Unexpected personal gain e.g. re-evaluation of what matters in life (1.1.3, 3, 3.1, 3.2, 3.2.1)	Inconsistency of CNS contact (role valued) (2.1.2)
	Specific information lacking (pathway, pre & post liver resection (2.2, 2.2.1)
	Feeling of being alone (1.1.2, 3.1.1)

Table 7.2: Summary mapping of positive and challenging experiences with related themes in Table 7.1

The three main components of hope: expectation, uncertainty and understanding were overarching themes, evidenced throughout the pathway. Table 7.2 is a means of translating the intellectual and philosophical findings from Phase 1 into the reality of clinical practice

and individual experience. It was also important to communicate these themes within the context of a rapidly involving treatment picture and dual site working.

It has to be made clear that presenting the data as experiences was not an attempt to reduce the data further nor an attempt to mould the data but the data required to be presented to convey the findings easily and plan an appropriate service response. Practical communication of the themes was deemed as essential in driving forward a service change and give momentum to planning change. In time pressurised, clinical environments, clear communication is a necessary precursor to successful change (Miller & King 2015,). One of the key components of this is using a common language that is easily understood by patients and health professionals alike (Miller & King 2015) so that a compelling case for change is made.

A cautious approach must be taken when viewing the table to understand that how the phrases correspond to the theme findings does not mean that phrases are disproportionately accounted for. This is purely an attempt as showing connection. As concluded in Chapter 7, hope has been the key element that links the experiences at every stage of the pathway of CRLM. A model of support was needed that reflected the overall feature of hope identified in the patient experiences and health professional focus group. This hope was seen in three main aspects throughout the experiences shared; firstly, a hope that was reflective of the story of treatment advances in CRLM. Secondly, an individual sense of hope despite personal difficulty encountered and lastly being helped to maintain a realistic sense of hope by health professionals. These three elements can be visualised in Figure 7.1 to help explain that the context of hope, the individual sense of hoping and the role that health professionals played in maintaining hope came together to show how integral hope was in this pathway. This hope was evident whether or not they were able to proceed to liver resection or not and very much reflects Kubler Ross's (1970) foundational work that a persistent hope is generally evident when prognosis is not favourable, stemming from her study of end of life in those terminally ill. Perhaps this reveals the complexity of hope as outlined in Chapter 5 in that it can be both an internal feeling set deep within our very being but also can be adaptable to different situations which are independent of outcome.

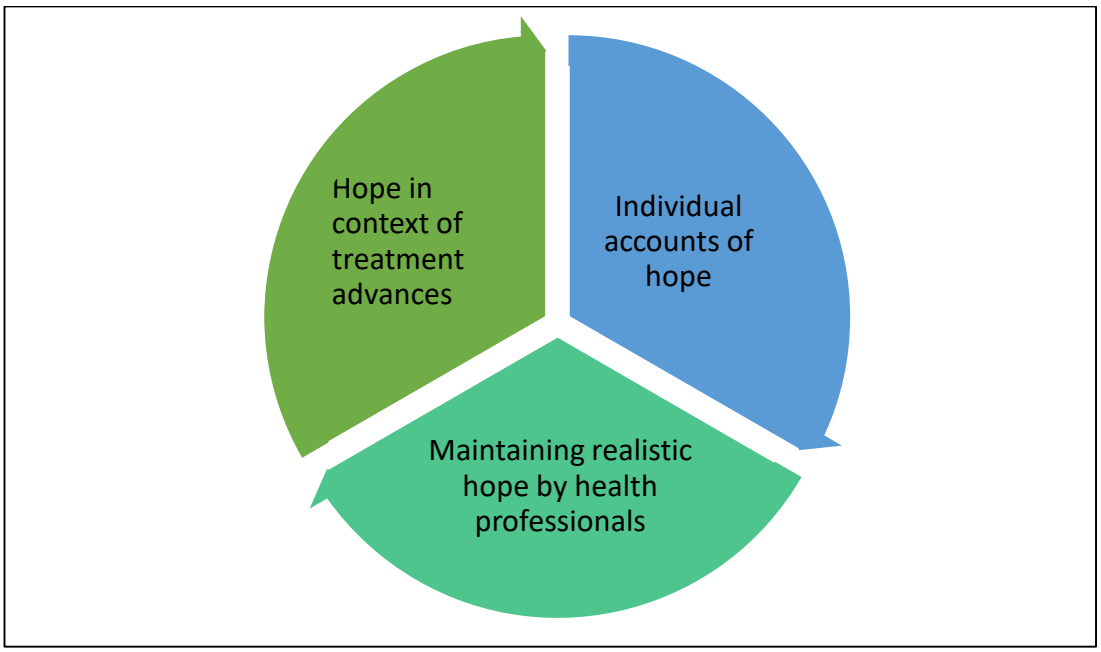


Figure 7.1: Aspects of hope identified in findings Phase 1

It was felt that as hope was such a feature of the CRLM pathway, whether viewed positively or with a more challenging connotation, the development of a new service model needed to utilise hope, celebrating both the success that was possible in this area but also being careful to provide a realistic sense of hope related to surgical possibility in response to the clinical presentation of each individual. What follows is a 3 pronged model of support that enhanced existing structures in place within the existing CRLM pathway. It is crucial to point out that the 3 central approaches were not changing the service but were enhancing already existing structures. There were of course, larger more structural changes that could be tackled in order to improve the overall pathway, such as ensuring ongoing liver surgeon presence in the colorectal MDM or seeking to improve timing of imaging but while this study flagged up the importance of such structural changes and is further given reference to in Chapter 9. It was not possible within the remit of the study to undertake larger issues which required more time commitment and negotiation, although the study may itself evidence the need for further structural changes. The response to the findings from Phase 1 was a nuanced change, picking up on the themes exposed from patient experience.

7.2.1 Deciding on revision of service delivery

The first step on deciding how to deliver a service in response to the findings was that there was no reason to suspect that the findings did not echo a similar perspective from other patients who were being considered for CRLM, certainly before any service change. Belief in

the study sample and findings was essential, otherwise change might not occur. For a qualitative study the sample size of 16 patients was a more than reasonable number to hold to this position. The findings resonated with the concerns found in the health professional focus group and in this way the findings had a mutual validity. Likewise, having that insider position within the team, the findings also reaffirmed the concerns shared amongst the specialist nursing team, some confirming the very concerns that were the catalyst for the study in the first place. My position as insider/outsider researcher has been set out from the inception of the study and I believed could not be detached from this part of the study either. My awareness of personal reflexivity was rooted in my knowledge of the pathway and patient group and my reference to the nurse specialist position. Although I was removed from the day to day work of the colorectal cancer team, I was still part of that team and therefore it was right that after data analysation, my colleagues were involved to find a response to help manage the overarching uncertainty encountered during the CRLM pathway.

Realising that the pathway itself was in a developmental stage as the number of referrals was gaining momentum, it was important to ascertain if some of the other larger U.K. centres had addressed concerns by being proactive about this CRLM patient group in particular. A professional UK network, of which I was a member, was emailed through a forum after the findings were gathered and a further literature review undertaken including assessment of conference papers but there were no incentives specifically to tailor support to patients in this pathway. In addition, a colleague and I visited a large national centre in North West of England which had recently made changes to structural aspects of their pathway. Again, while it was not the structural aspects that were our specific interest, this did allow for meeting with the CNS team who were involved with CRLM patients. Meeting with the CNS team proved valuable and in particular we took away some core messages about communicating the next steps of the pathway for individuals, in a pathway that is constantly evolving and creates uncertainty within that process. While their HPB (hepatobiliary) unit manages a number of referrals over a widespread area similar to our HPB unit, at this particular centre, the hepatobiliary CNS team took more of a direct role with CRLM patients. This highlighted how each area and colorectal liver metastases team had evolved differently. Each national network is constrained by geography and additional factors so that who may be the best person to provide support service in one area may be different in another. In our area at the time of designing the service intervention, the hepatobiliary CNS was a singular post and was funded to primarily focus on primary hepatobiliary cancer. There was not the

remit for this postholder to engage more fully with the CRLM patients due to funding constraints and workload requirements. In addition, a further interventional literature review was undertaken at this stage to ensure that no support interventions with a CRLM patient population had been published during this time.

The results of data analysis were discussed primarily with the colorectal nursing team and fed back to the study steering group, giving way to the three pronged model of support outlined in the implementation of change diagram, Figure 7.2., as seen overleaf.

An important element for the nursing team was the underlying ethos that the new model would have drawn from the data in the study. So much of the support work offered from the specialist nursing team has been understanding the relevance of an individual's life cycle to cancer. All team members draw heavily upon understanding the context of cancer according life cycle, key relationships, social contexts and personal beliefs. Understanding this is critical in caring more holistically for individuals as all too often the cancer adds to the burden of existing life situations but is not only the main consideration. How cancer impacts on life has to be understood in what *is* life for that individual. In understanding this ethos of care and in considering the model of support to future CRLM patients, I was drawn to Rolland's publication in 2005 in a supplement to the *Cancer* journal, entitled 'Cancer Survivorship: Resilience Across the Lifespan'. I refer to the name of the supplement as I think it is pertinent that the words, survivorship, resilience and lifespan reflect the spirit of the progress made in CRLM treatment. The paper was discussed with the team in addition to the findings.

In Rolland's paper, the Family System Illness model was used to help manage the stresses and uncertainties of cancer. The value of this model was identified as:

> *"it informs clinical practice to identify predictable strains and to facilitate optimal coping and adaptation." (Roland 2005, p.2585)*

I will come back to draw out some important elements of this model in Chapter 9 in relation to the application of hope but the Family System Illness model allows for understanding the illness not just in the context of the family life cycle but also against the patterns of illness across the illness trajectory. These patterns included variations in terms of onset, course, outcome, incapacitation and the level of uncertainty (Rolland 2005). Individuals root their experience in their diagnosis (onset), relate to continuing treatment (course), understand the reality of secondary disease (outcome), experience side effects of treatment (incapacitation) and seek to maintain a realistic hope (level of uncertainty).

This descriptive pattern of illness fitted well the trajectory of illness revealed in the findings in Phase 1 where the overriding feature of the CRLM had been in maintaining hope amidst uncertainty. In this way there were two continuums running, the trajectory of family life and the trajectory of illness. Two key sentences which stood out for me in the outcome and level of uncertainty patterns of illness in Rolland's article were the following quotations,

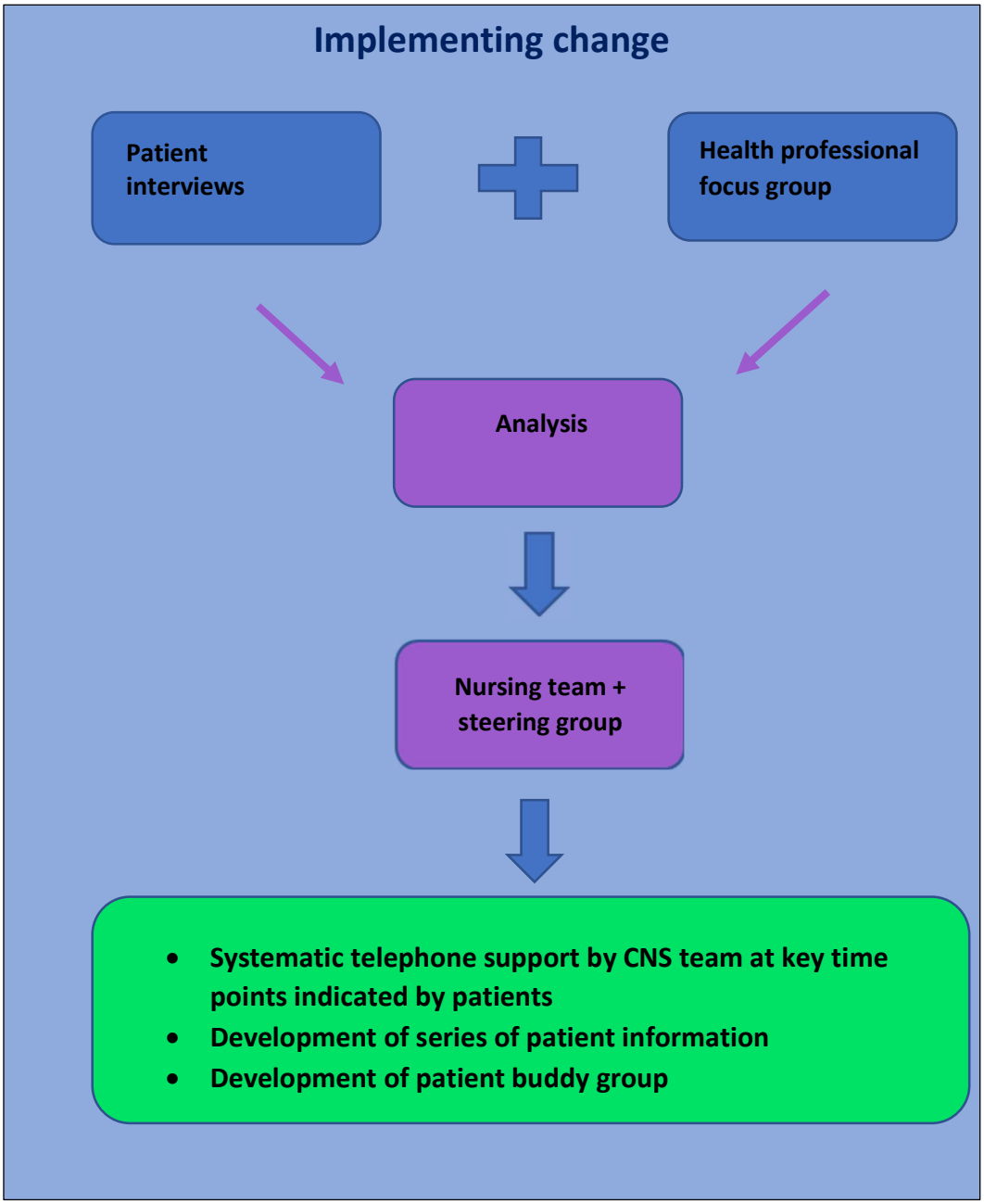


Figure 7.2 Implementing change: a responsive model to patient interviews Phase 1

"The extent to which a chronic illness leads to death or shortens an individual's life span has a profound psychosocial impact" (Outcome pattern) (Rolland 2005, p.2586)

and

"Generally, families that are able to put long term uncertainty into perspective ae prepared best to avoid the risks of exhaustion and dysfunction"(Level of uncertainty pattern) (Rolland 2005, p.2586)

The quotation from the outcome pattern of illness has a particular pertinence to those being considered for CRLM. As discussed in Chapter 2, there are few other comparisons in cancer where surgery is used to remove a secondary liver disease with the intention of significantly improving survival or completely resect diseased tissue. Holding this in mind while considering the fluctuating pattern of uncertainty throughout the liver metastases resection pathway, underscores what a turbulent time this process can be and how it has the potential to create an elongated period of uncertainty which may formerly not have been seen in this area when there was no surgical treatment option. The second quotation, hints at the work undertaken in order to develop the Family Systems Illness Model which drew on clinical experience with over 800 families at the University of Yale and Chicago. This suggested that in long term chronic conditions, uncertainty was always going to be integral to living with the condition but in order to create resilience, the longer term uncertainty had to be set aside in order to adapt and avoid a risk that may be harmful to the individual. This article summed up all that had been important in our development as a nursing team and was an important parallel to setting the context of the findings of Phase 1. The model that we choose to help support patients with potentially colorectal liver metastases, needed to be flexible enough to help identify and manage expectations.

7.2.2 Team inclusion and ownership

As indicated in the previous section, the existing nursing team was very much a part of formulating a response to the data analysis. They were the key team members who would be co-ordinating the support model. It was vital that they felt the model was not only an appropriate response to the data but also would be feasible with current team resources. The nursing team needed to have confidence in the new model and have ownership of knowing how it might work or what might cause it to fail. It was also important that the nursing team could voice concerns upfront. This part of the interim period had a duration of four months. Perhaps being conscious that the study required to run to time due to resource

allocation, it could have been tempting to have been descriptive about what the model might have been. Yet, inclusion and ownership and discussion were essential components across two sites delivering care. Failure to have done this may only have led to further time delays later in the study or failure of the nursing team to be able to commit to using the model. Due to resource allocation the colorectal nursing team took ownership of the model and were responsible for using it with new patients being considered for liver metastases resection. In addition, the hepatobiliary nurse specialist was also closely involved with discussing change. This helped to build on existing links with the specialist resection centre but also understand how further collaborative working could be furthered.

7.2.3 Rejection of alternative considerations

During the decision making process outlined in Section 7.2.1, time was taken to consider other tools which may be useful for gaining an insight into this time of active waiting for patients. During this time, the Holistic Needs Assessment Tool as developed by Macmillan (Snowden et al 2015) was also considered. The nursing team had experience in using this tool within follow-up practice finding it valuable in highlighting needs and ongoing treatment issues. At one stage the Holistic Needs Assessment was considered as to whether it could be given to patients at specific time points in the pathway in conjunction to the timings on the telephone model of support (Figure 7.2). It was briefly thought that this could be used instead of the SWIFT tool discussed in Section 7.3 but it would have given a different feel to the method and perhaps have felt too much like a tick box exercise on the phone rather than utilising the SWIFT tool within a conversation with a skilled component. This consideration was rejected by asking the question as to what purpose it served in eliciting the experiences of patients on the pathway. While the tool was valuable in a follow-up setting or after treatment periods, a model was desired that didn't just focus on late or longer term effects of colorectal cancer treatment but that could also encompass these issues. It is clear that a number of patients do have late effects from colorectal cancer treatment (Denlinger et al 2009) particularly in pelvic surgery and radiation for rectal cancer (Knowles et al 2013, Sanoff et al 2015). A furthermore fitting reason for rejection, was that its use did not adequately reflect the use of the hermeneutic phenomenology in the same way that the SWIFT tool did and this will be picked up in Section 7.3.

In the same way quality of life tools were also rejected such as the EORTC C-30 (general) and C-38 (colorectal cancer specific) (https://www.eortc.org/) and the FACT-C

(https://www.facit.org/facitorg/questionnaires) tool as this would have introduced a mixed methods approach which was considered to have detracted from the qualitative methodology. Once again the focus was on uncovering the experiences of those on the CRLM across a timespan of potential treatment and both reflections on the value of collecting quality of life data and discussion with the hepatobiliary surgeon on the steering group, confirmed that this would take the study in a different direction.

7.3 Provision of CNS telephone support

Taking into consideration the results from the data analysis, one of the key interventions to addressing the key concerns of how to manage realistic expectations was the provision of a telephone model of support run by the colorectal CNS nursing team. A large proportion of the nurse specialist workload is carried out by this approach. There has been a significant increase of interventions led by cancer nurses to meet the growing needs of those affected by cancer (Charalambous et al 2018). A key document highlighting the value of the nurse specialist role, based in rheumatology practice, outlined that the significant contribution of managing patient care was achieved by telephone, (Leary & Oliver 2010)/ Warren et al 2012 . Previous work by Leary et al (2008) had identified that 50% of the clinical caseload was managed by telephone workload, predominantly in providing advice and by so doing could reduce GP consultation and often hospital admission. Much earlier work by Hughes et al (2002) had shown that having a telephone caseload could enhance NHS value and cost-effectiveness. Certainly, within our practice, an audit of our time allocation, echoed the findings of Leary et al (2008) showing our workload as equivalent to 50% of clinical time allocated to the telephone.

There were several benefits in using the telephone as the main support model. Firstly, when considering how to bridge care that traversed three potential departments (surgery, oncology and hepatobiliary surgery) and two major teaching hospitals, telephone support is able to transcend physical barriers and make support more readily accessible. This method is suited to being responsive when communicating within a pathway that was fast paced and could easily change direction. Secondly, communicating by phone was already a method which was used within the practice, especially for passing on results of post-operative pathology via a well established telephone clinic. It was the practice of the nursing team to seek an enabling approach to gain acceptance of this method so that those not wanting this method of communication could come back for a face to face clinic consultation. This method

was generally considered acceptable and more efficient, reducing hospital visits and speeding up knowledge of plans for treatment. With 66 million people in the UK and approximately 94% of all adults owning a mobile phone (Henshaw 2018), there has been a cultural shift of the necessity of efficient communication generally for everyday life and relationships in that it has become a communication norm for all generations. The out of hours healthcare of NHS 24 has embodied the telephone to triage more urgent cases to be seen at local out of hours centres across the UK. Thirdly, the colorectal nursing team were familiar with this method of communication having developed and adapted communication to take into consideration the lack of face to face contact and inability to read non-verbal communication. It could be argued that as a result there is a particular type of skill to this clinical telephone communication. While it takes the basis of a conversation, it seeks to address concerns in a holistic manner, listening to tone and giving opportunity to expand on other areas where they patient might want to direct the conversation. It is also requires advanced communication skills to deliver this type of communication and is something of a skill that has to be acquired in conjunction with knowing the overall colorectal pathway. For this reason, two of the more senior team members took responsibility for the telephone support and also meeting the patients at diagnosis to act as the main point of contact throughout the pathway. While the systematic support by the CNS team at timely intervals was the main feature in this enhanced pathway compared to the pathway in Phase 1, offering support without a framework was not thought to be enough. A tool was required that would provide a holistic framework for conversation and assessment and that would also honour the concept of the Family System Illness model discussed in section 7.2. The tool chosen was known as the SWIFT tool and is explained more fully in the following section. The acronym encapsulates the following areas of life which may be used for assessment by a clinician, in this case the nurse specialist and are as follows;

- (S) Stress/coping
- (W) Work/home
- (I) Ilness/condition
- (F) Friends and family
- (T) Things I like to do

7.3.1 Incorporating the SWIFT tool

The team was first exposed to the SWIFT tool by attending a course entitled 'Developing Practice', designed to support experienced clinical staff to address psychological needs of their patient caseload. This was designed by the Psychology Directorate, within NHS Education for Scotland in 2013 and in association with NHS Lothian. The complete SWIFT tool can be viewed in Appendix X. The tool was designed on the back of an *Emotion Matters* series (now an e-learning module) which came as a result of a document entitled Emotional Support Matters (2010). In a way, the report formed the policy bedrock upon which Emotion Matters was built and in turn which produced the SWIFT too. This was published in response to people with long-term conditions needing a more holistic approach to their care. At the time the Psychology Directorate had been involved in work with practitioners who felt they did not have the skills required to address emotional issues when working with people living with long-term conditions in conjunction with the Long Term Conditions Alliance Scotland, (LTCAS). The aim of the Emotion Matters series was firstly to increase understanding and awareness of the psycho-social aspects of living with a long-term condition and secondly to provide skills that would enable a more holistic, collaborative and person-centred care.

In many ways, the timing of the Emotion Matters series looking at the emotional needs of individuals for long term conditions was fortunate for the timing of the study. This was at a time when the overall treatment of CRLM was emerging for many as a long-term chronic condition. The Emotion Support Matters developed from work with groups of individuals with long term conditions had clarified that,

> *"People with long term conditions want holistic support that includes emotional and psychological support as part of an integrated service and not just as an add on." (LTCAS, 2010, para.5)*

This echoes many of the sentiments of the Family Systems lllness Model and those that we sought to identify in practice. What the Family Systems lllness Model lacked was the practical 'how to' application for conversational assessment. The suitability of the SWIFT tool was that it was broken up into different areas with prompts to cover each area. By naturally covering each of these areas, knowledge was gathered that could then be used to help address any concerns, signpost further or take other action. In addition, it was also considered useful to use the widely available, Hospital and Anxiety Depression Score (HADS) tool, (HADS 2016) should the conversation suggest this. This is was unlikely to be undertaken on the initial call

but followed up with a further telephone call at the clinical judgement of the nurse specialist. The consideration to include this tool, if needed, came from the study findings and the experience of the one participant in particular who had three liver resections and others who had spoken about anxiety and low mood during chemotherapy (Section 6.1.2.3, 6.2.2.1). It is important to note that there were three main calls in which the SWIFT tool was used (four, if an individual had neo-adjuvant or down-staging chemotherapy) but there were also additional calls depending on the needs of the individual or family members. Using the SWIFT tool gave form and structure to the conversations at key time points.

Development of telephone timeline

The agreed timepoints as seen in Figure 7.3 (overleaf) show four main areas that that came from the findings. These were both a blended interpretation of the data from my position as a researcher and an insider and also discussion of the findings with the immediate colorectal nursing team. The time points were deemed particular points of high anxiety either due to reflecting on what the participants had revealed in the interviews in Phase 1. The time points chosen to carry out the SWIFT tool were diagnosis, key management decision, midway point of chemotherapy and post-resection or equivalent timeframe if no resection. Patients who were not able to proceed to liver resection still had a telephone call after a decision of liver inoperability was made as this allowed the nursing team to assess the impact of this decision and continue to support this group of patients. This was carried out approximately 2-3 weeks after a decision of no liver resection was made. This had particular relevance for this group of patients in allowing them to reflect on that decision and pre-ceding treatment which despite participating in, had not resulted in liver resection. Learning how this experience affected others might also be of value and help to shape support for others in the future within the context of hoping for potential liver resection.

7.4 Development of local patient information

As a nursing team we were aware that the current patient literature on CRLM was not adequate. As often is the case in medical developments, the accumulation of literature, particularly literature that is practical in nature is lacking (Tran et al 2019). As such there exists a gap between what is accurate and what is possible and getting access to specific information is difficult and has the tendency to leave individuals feeling overwhelmed or disheartened by what they read. Certainly, at the time of commencing this study patients often reported that there was little by way of patient information that suggested anything of

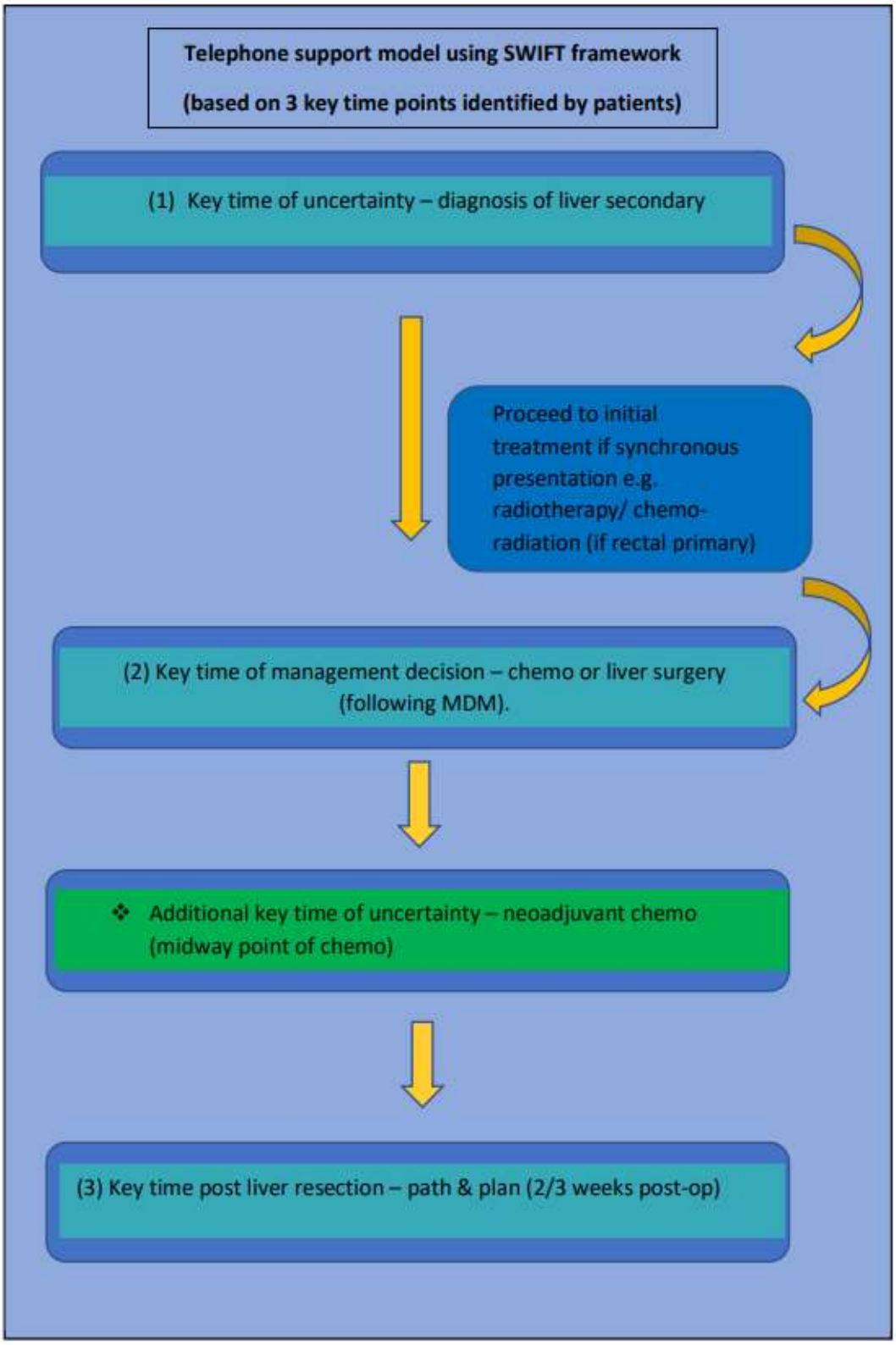


Figure 7.3: Time points for telephone SWIFT assessment

the hope of liver resection. Much of it was related to the prognosis of liver metastases and survival figures and which did not seem relevant if surgery was a possibility. Of the information that did relate to CRLM, patients often relayed to the nursing team, that much of it was too technical and cumbersome with a lack of understanding of decision making or practicalities about the overall process. This was highlighted to me by the following situation, when after publishing an article in a UK nursing journal (Sherwood, 2015), a relative of a patient who was being cared for in New Zealand contacted me by email to ask further questions as her father was due to undergo a liver resection for secondary bowel cancer and she was having difficulty finding relevant information online. At the time she also expressed appreciation as the article had allowed her to hope by knowing that her father was eligible for liver resection and in detailing some of the context of that decision-making process. At the time of writing she was working in America and could not be with her father for a few weeks. While this did not influence any of the response to the findings, it did confirm the importance of having easily accessible information about the process of colorectal liver resection that was relevant to our local practice and setting.

The decision to produce a series of leaflets came from listening to the stories of the participants in Phase 1 and in knowing that the potential for heightened anxiety from the internet in the absence of any relevant site specific was likely to occur, either in patients or family members. Three information leaflets were designed with the colorectal nursing team and joint input from the hepatobiliary nurse specialist, gleaning information that was lacking in the CRLM liver pathway from Phase 1 participants. The leaflets were not only to pick up on what information participants had found lacking but also were aimed at explaining the overall process and be reflective of each area moving from a diagnosis to treatment and aftercare/follow-up pattern. This also aligned with the model of telephone support and reinforced the pattern of more formalised support and assessment with the SWIFT tool. The leaflet series was produced in the interim time period of four months between Phase 1 and Phase 2 and approved by the local communication team.

7.4.1 Integrating key information from interviews

The leaflet series incorporated the following titles, as seen in Figure 7.4, below.

- *When bowel cancer spreads to the liver; understanding surgical management*
- *When bowel cancer spreads to the liver; your surgery*
- *When bowel cancer spreads to the liver; your recovery from liver surgery*

Figure 7.4: Patient information series

They can be viewed in the relevant Appendix XI – XIII. All leaflets contained contact details of the hepatobiliary and colorectal nurse specialist teams to reinforce accessibility and allow easy contact. Close working was maintained between the local hospital communication team to ensure that the leaflets were in accordance with reading acceptability and local communication guidelines. Each information leaflet in the series flowed from diagnosis to surgery to recovery and was designed to be specific to the local site but also to be applicable to a range of patients being considered for CRLM. All leaflets began by setting out the purpose of the information contained within and focused on incorporating what had been lacking or important to stress from the previous participant sample. Table 7.3, overleaf, details the key messages that had come from the findings of Phase 1 which were essential to highlight to potential patients being considered for colorectal resection.

7.4.2 Leaflet review process

After the leaflets were compiled by the colorectal nursing team and hepatobiliary nurse specialist, the leaflets went back for review to the steering team and immediate surgical and oncology consultant team. Positive feedback was received and the series was welcomed. There was also a suggestion that a similar series was developed for the consideration of a lung resection for secondary lung metastases from a colorectal primary. The leaflets were reviewed by eight patients who had conducted the interviews and feedback was sent by post. The leaflets were also reviewed by a further five patients attached as patient representatives to a local area network.

Leaflet title	Key aspects of inclusion from Phase 1 findings
When bowel cancer spreads to the liver; understanding surgical management	1) Process of surgical management 2) Multidisciplinary approach 3) Planning individual treatment essential 4) Planning effective treatment requires time 5) Explanation of liver metastases – not liver cancer 6) Explanation of secondary 7) Who is involved in decision making 8) Possible treatment options 9) Follow-up 10) Ongoing support/ access to previous patient
When bowel cancer spreads to the liver; your surgery	1) Current surgical management 2) Preparation pre-surgery 3) Potential Portal Vein Embolisation (PVE) 4) Potential cancellation of surgery (liver transplant unit) 5) Immediate aspects of care 6) Mood 7) Going home 8) Follow-up 9) Ongoing support/ access to previous patient
When bowel cancer spreads to the liver; your recovery from liver surgery	1) Early recovery post-operativeperiod 2) Longer term recovery 3) Fatigue as result of resection 4) Alcohol intake 5) Sleep 6) Resuming normal activities (including sexual activity) 7) Work 8) Mood 9) Follow-up 10) Ongoing support/ access to previous patient

Table 7.3: Key information aspects of inclusion in liver series

The local network welcomed the leaflet series and once formalised, requested to have them accessible online. Two oncology consultants also took the leaflet series to outlying clinical areas so that they could be adapted and considered for use in those areas. The use of the series was also reinforced and supported by the telephone method and helped to introduce the idea of peer support in addition to professional support available.

7.5 Establishment of patient buddy service

To build on the provision of the CNS telephone support and the development of local patient information, a considered action in response to interpretation of the data was to establish a

patient buddy service. This was something which the nursing team had often contemplated before but had not set up formally. Previously, the nursing team, had on one off occasions, linked patients at any stage of primary or secondary cancer at the request of patients who had indicated interest in this. What had prevented any formal establishment until this point had included concerns about how effective interactions might be, perhaps more from a paternalistic point of view that interactions might only cause harm or confusion. In addition, there were concerns that patients who had volunteered as a patient buddy might perhaps become more heavily embedded in the cancer process when they might feel that they wanted to 'move on' and put their cancer experience behind them. A final concern was the sustainability of such a service in that managing training, new volunteer buddies and matching might involve on an already busy nursing service.

At this point it is worth reflecting on some aspects of buddying in general before outlining how the service was established, in order to understand what the service was and more importantly what it was not to be. It was also important to consider what attributes were important to the nursing team and how they wanted the service to be experienced by future patients.

A definition of buddying by Campbell (2015) describes buddying as

> *"an arrangement in which persons are paired, as for mutual safety or assistance". (Campbell 2015, p.992)*

This definition hints at a commonly understood aspect of buddying in that it is support for peers. There is not normally a sense of a hierarchical relationship structure. Already though this definition raises potential concern about how might peer pairing or matching take place. As much of the success of the buddying and original intention might only be achieved depending on personal qualities of the buddy and on that relationship develops. Simpson et al (2017) recount that,

> *"In most cases the 'buddies' are individuals who have been through similar experiences as the person they are 'buddying' and as such they are able to pass on their learning and knowledge based on first-hand experience" (Simpson et al 2017 p.3).*

It was that peer aspect of support that from the research data in Phase 1 was thought to be missing from the process and being able to offer this as an additional resource to tap into was seen as something particularly important when health professionals did not themselves

have that 'first-hand experience' of what it was like to experience the pathway towards CRLM. Incorporating a buddy service was also thought to lend itself to the Gadamerian philosophy influencing the study, in that there was an awareness of the limitations of our understanding as health professionals to understand the CRLM pathway as much as we knew the possible pitfalls of the pathway, we did not share knowledge from a first-hand experience and that this first-hand knowledge could offer something unique in addition to the other forms of support offered.

The concept of 'buddying' is evident in a number of settings but as a review led by Simpson et al (2017) for CLAHRC NWC (Collaboration for Leadership in Applied Health Research and Care North West Coast) points out there is a lack of literature relating to the theoretical underpinnings of the term 'buddying'. The review while undertaken as a response to support the use of community resources in the North Coast of England, has gleaned some relevant understanding of the buddying term. There are of course some generally understood elements of enabling and supporting that a buddy would offer when teamed up with another. This is seen in the different types of contexts it is applied to. From their review, Simpson et al (2017) report that it is commonly been promoted in the workplace when it is used as a practical intervention that is used to support an individual starting a new job. This may be a new recruit, student or apprentice. Within health care, buddying can often be part of induction for junior doctors and student nurses (Honney et al 2012). It has also been identified as a social and psychological support intervention for physical and mental illnesses (such as cancer, type 2 diabetes and depression) and within the public health setting, buddying has been used to promote and encourage healthy lifestyles, such as smoking cessation and increasing physical activity. (Simpson et al 2017). Additionally it has also reported use to help to counteract school bullying (Dockett & Perry 2005), help foster educational support (Campbell 2015) and support military personnel return to civilian life (Greden et al 2010).

While the introduction of a patient buddy service in this research study, was not based on what was already in the literature, it is worth noting that there is limited evidence as to the effectiveness of buddying programmes. Startlingly, Simpson et al (2017) suggest that this is because the majority of studies have been qualitative and descriptive in nature rather than randomised controlled trials (RCTs), suggesting that use of qualitative research does not have value in the experiential nature of buddying! This would seem to contradict the very nature

of applying suitable methodology to the research question. That is not to say that RCTs have no place in addressing the question of whether buddying programmes work in cancer, but the richness of qualitative work should not be omitted. Campbell et al's paper (2004) reported on the efficacy of peer support programmes some fifteen years ago previously and although it included a few RCTs, there remains little published in the literature including RCTs. Perhaps this is about to change, as a resurgence of interest seems to have occurred around the use of multi-dimensional support in cancer including peer support. Simpson et al (2017) drawing on the work of Nigah et al (2012) in the use of buddying in professional private sector suggesting that this may be more due to economical reasons rather than any real evidence. Buddying has often been used as a method of encouraging behavioural change, i.e. smoking cessation, weight loss and one can see that it the social sector, cutting down on such programmes might be a way to reduce cost. However, the reality is that buddy services need to be monitored by professionals for participant safety and it would be alarming to think that increasing peer support would be a way to cut costs and thereby risk reducing health professional input and that given from the charity sector. However, from abstracts and conference papers, it would seem that several RCTS are being considered within the cancer setting to look at this issue. RCTs, I suspect, may not adequately get to the heart of the complex matter of uptake.

Nonetheless, discussion with the nursing team on presentation of the findings, had agreed that in order to help address some of the issue pertaining to being considered for CRLM resection, namely uncertainty, isolation and protection of self as distinct from the input that family or friends could give, that establishing a patient buddy service might be an apt intervention to adopt in this smaller patient group of patients with liver only metastases who may be eligible for resection. In addition, the results had shown that 9 out of 16 people had offered voluntarily, without prompting, to speak to others should that be something which may be helpful. This was willingness came from an understanding that they may be able to share or understand aspects of what another patient may encounter. It also came from an attitude of thankfulness and a desire to give something back in the realisation that they had been able to proceed to liver resection or had been given the opportunity to have been considered for potential resection as the following two quotations emphasise;

> *"If I can help in anyway. I'm quite happy to be involved and speak to others, to do something so that people see I've been through it. That's*

important and I wouldn't be here now had I not the opportunity to go through this". (Chris)

and

"If there are others out there who have been through a similar thing and might find it useful to speak to me. They need to know that there is still a day to be lived". (Julia, no resection)

From Phase 1, the drive for building peer support was to meet the needs of isolation and managing uncertainty from the uniqueness that peer support could offer, something which was missing from the previous phase of study. Indeed, the following quotation, highlights the attributes that the nursing team wanted in the patient buddy service.

"In general, peer support has been defined by the fact that people who have like experiences can better relate and can consequently offer more authentic empathy and validation. It is also not uncommon for people with similar lived experiences to offer each other practical advice and suggestions for strategies that professionals may not offer or even know about. Maintaining its non-professional vantage point is crucial in helping people rebuild their sense of community when they've had a disconnecting kind of experience" (Mead and MacNeil 2004, p 4).

It was true that from the data in Phase 1, patients had undergone a disconnecting experience that had taken them further than a diagnosis of primary cancer alone had taken them, in placing them closer to the potential non-curative aspect of their illness and that had disconnected them from life as they knew it, and for some changed their sense of connectedness to family, friends, work and social situations. It seemed wise to attempt to introduce peer support as a way of building in additional community. There was recognition from review of the data of the role that families and individuals played in managing patient wellbeing but peer support was recognised to be a reciprocal process as the above quotation illustrates. It would have been perhaps naïve to think that patient volunteers were 'finished with' or 'over' their experience of liver resection and that there might also be a therapeutic effect of future interactions with other patients.

7.5.1 Setting up the buddy service

The reciprocal nature and level of personal involvement at a significant time point in a patient's life meant that patient selection for the buddy service was crucial. In reality, there is little recorded in the literature about the transparency of this process. A more inclusive approach might be to advertise within hospital clinic settings and invite all were who eligible

to come forward for buddy training, yet being honest the paternalistic side of the health professional, prevents this from happening as we all can recall patients who might come forward yet may not acquire or be able to develop the skills required to be a patient buddy. For example, a willingness alone to help others was not simply enough and some may find it difficult not to use the interactions with the current patient to project their experiences too strongly which would unlikely prove beneficial. Additionally, patient character arguably requires to be understanding and balanced, putting the focus on the current patient, despite their own previous experience.

Having had a sample of patients for Phase 1, the colorectal nursing team selected patients who had been involved in patient interviews. One of these selected was one of the pilot interviewees. The benefit of inviting these patients, was that they had been familiar with the intention of the study and its aim to influence future practice as outlined in the study information sheet but they had also, at the time of their interview, volunteered through the interviews to speak to other patients. There may have been an element in which the interviews had some therapeutic effect as they reflected on their own personal journey with diagnosis and treatment. This concept is later picked up in the discussion in Chapter 9. The buddy group characteristics can be viewed in Table 7.4 overleaf.

Potential patient buddies were contacted by telephone by the nurse specialist who was known to them and invited to consider the invitation to become a patient buddy. They were given initial information about time commitment and training and time to reflect on the invitation. All five agreed to come to a one off in-house training but it was stressed that this did not commit them to becoming a buddy. The training took place on one of the main teaching hospital sites in a cancer charity facility. The cancer charity was skilled at running the training, regularly facilitating a number of group sessions for cancer patients and their families throughout the week. The training was adapted in conjunction with input from the colorectal nursing team in order to make it more specific to the colorectal liver resection pathway. The training took place in an evening in October 2013 and was intentionally structured to flow from reflection on the buddies' own experience to that of what characteristics might be needed. The centre lead facilitated the training and in addition to the five potential buddies, one colorectal nurse specialist was present and I was present in an observer capacity. No methodology was applied to the observation as this section of the intervention could not have been predicted at the outset of the research study. The evening

was roughly split into two parts with a break in the middle. Box 7.1 below, outlines the content of the evening.

Sex	Age at diagnosis	Cancer Primary	Presentation of liver metastases	Sequence of treatment
Female	62	Colon	Colorectal follow-up	Primary surgery Chemo Liver resection Further 2 liver resections
Male	58	Colon	Synchronous	Synchronous resection Downstaging chemo Liver resection Further liver resection
Female	65	Colon	Synchronous	Synchronous resection Chemo
Male	63	Rectal	Colorectal follow-up	Short-course radiotherapy Primary surgery Chemo Liver resection
Male	55	Colon	Synchronous	Primary surgery Chemo Liver resection

Table 7.4: 'Buddy' characteristics

Buddy training event – content
<u>Part 1</u> - Ground rules - Establishing safety and confidentiality - Personal reflection on own journey to liver resection (in pairs). Exercise to condense their own cancer story, involving highs and lows of experience. Attention paid to skills required in listening to the other. Reflection on what was useful.
<u>Part 2</u> - Presentation and discussion on positive attributes required to buddy - Practicalities to consider in setting up a buddy meeting - Navigating more challenging situations that may be encountered

Box 7.1: Content of buddy training evening event

It was agreed that the CNS would act as a liaison point and would establish how the patient wished to be contacted, i.e. if they wanted to ring the buddy or vice a versa. Meeting was often seen as preferable and was encouraged to take place within Maggies for the first introduction so that a safe and familiar place of meeting was established.

At the end of the evening the participants voiced that they had enjoyed the evening, in particular, finding it helpful to have met others who had gone through a similar experience of being considered for colorectal liver resection. All of the five participants agreed to be patient buddies and did not wish further time to think about it. It was stressed that being available as a patient buddy meant that it could not be guaranteed how frequent their involvement might be required and that they could still opt out from the buddy service at any time. The findings relating to the buddy service are discussed in the following chapter as part of Phase 2 overall findings.

Summary 7.6

This chapter has detailed the interventional approach as a response to the findings in Phase 1, which previously presented in Chapter 6. The chapter has been purposefully reflexive in nature, revealing how the approach was arrived at by interpretation of the data as both an insider and outsider and importantly with the inclusion of the colorectal nursing team who were key in implementing the approach. It also lends itself to Gadamerian philosophy of a fusion of horizons as detailed in study methodology in Chapter 5. The model chosen was a three-strand approach involving a telephone support model using the SWIFT tool assessment, provision of a series of patient information leaflets and the development of a patient buddy resource. The next chapter presents the findings of a second phase of patient interviews and health professional focus group which was completed with a consecutive series of patients after the implementation of the enhanced support pathway.

Chapter 8

Looking again; examining new horizons - findings from Phase 2

"To think historically always involves mediating between those ideas and one's own thinking. To try to escape from one's own concepts in interpretation is not only impossible but manifestly absurd. To interpret means precisely to bring one's own preconceptions into play so that the text's meaning can be made to speak for us" Gadamer p.398 (Gadamer, 2004).

8.1 Chapter overview

One of the dilemmas afforded to qualitative research is how to deliver the findings so that the form selected shines light into the understanding of the reader in the same way that the researcher has viewed the interpretation of the data. This demonstrates a consanguinity with the very concern of hermeneutics, being the art of understanding and the intention to make language understood (Zimmerman 2015). In this instance presenting data from two phases of qualitative interviews is indeed challenging, both from the volume of qualitative data afforded from two phases, and in the task of displaying the findings from a study utilising phenomenology and incorporating a service revision. From the outset, the purpose of the phenomenological inquiry was to have a practical intention in driving forward a service change as outlined in Chapter 7. Di Cesare, as translated by Keane (2013) exemplifies the practicality of hermeneutics when he writes,

"To understand means to apply; understanding is always put into practice and thus becomes a form of action in itself, in the world, and with others" (Cesare 2013 p.109).

To this end, this study has been unapologetically practical in nature. It has sought to utilise the theoretical to expose the practical value of examining the underlying patient experience of being considered for liver metastases. In his 1972 essay, 'Hermeneutics as Practical Philosophy', Gadamer emphasises the central tenet as he sees it of hermeneutics, that understanding ought to be applied (Dobrosavljev 2002). Here hermeneutics takes on what Gadamer sees as an ethical dimension whereby it goes beyond the task of understanding but extends to change. Appreciating this allows the reader to see the continued suitability of phenomenological hermeneutics as a methodology to this study. This chapter is primarily concerned with presenting the findings of determining service revision but will also refer to and validate previous themes as identified in Chapter 6 and seen in Table 8.1 within this

chapter. Further iInterpretation will utilise concepts applicable from Gadamer's practical hermeneutics, mainly being, authenticity, fore-structure, temporality and history. As in Chapter 6, pseudonyms (first name only) have been adopted within this chapter to protect the anonymity of participants.

8.2 Revisiting methodology

In reflecting on how most fittingly to present the data, the realisation cannot be escaped that I have been part of this research alongside the experiences of the individuals and in so doing have had my own personal research journey. This I recognise arrives at a time when I can more fully appreciate those words of others encouraging me to undertake this study for the journey that I would go on as allude to in Chapter 5. A central underpinning of Gadamer's work in Truth and Method (1960) is the idea that our understanding in never only subject-oriented in behaviour and is always historically limited. As Duška writes,

> *"The notion of prejudice loses its negative connotation and represents not only the link with our tradition, but also the original source of all our judgments." (Duska 2017, p.219).*

Undeniably, my position as a researcher has been difficult to disassociate with this work, on two counts; firstly my position as interpreter on a professional level means that I will always bring something of my own foreknowledge to the interpretation of the interviews and focus groups and secondly my position as researcher with an insider/outsider dual role will add a further level to interpretation. Rather than ignoring this level of involvement, Gadamer sees one's own position as relevant in the interpretation, as the opening quotation of this Chapter vigorously claims.

As language is the determination of hermeneutics, a concept explored extensively through Gadamer's Truth and Method (Gadamer 2103), the sense of meaning has been weaved from the process of the interviews themselves, the committing of the words to written transcript and through reading and re-reading of these texts. The use of Interpretative Phenomenology Analysis (IPA) as chosen analysis methodology discussed in Chapter 5 has been particularly useful in focusing on the breadth and depth of the data contained within the transcripts, giving due recognition to the complexity of the participants' accounts. This has also reflected the concept of the importance of interpreting the part and the whole as exemplified in the hermeneutic circle.

This occurs on two levels. The use of IPA as a methodological framework allows dual aspects of interpretation by participant and by researcher. Through the process of data analysis, it can be seen that the patient is both participant and interpreter and the researcher is viewed as both observer and interpreter. Analysis is an attempt to understand what it is like to stand in the shoes of the participant. As Pietkiewicz and Smith (2014) outline, analysis is both descriptive because it is concerned with how things appear, and interpretative because it recognises that there is no such thing as an uninterpreted phenomenon. While the participant might share what they know of their experience, Gadamer holds that we (or in this case the researcher) will interpret this experience with any foreknowledge or background to that situation or indeed any prejudices they may hold (Gadamer 2013). This is an important reality to be aware of during interpretation, particularly with the pre-knowledge that I had of both colorectal cancer and the liver metastases resection pathway. For myself, looking at interpretative meaning through horizons was hugely significant as it occurred on multiple levels within the study, where all viewpoints from both phases could be pulled together to arrive at a more complete sense of meaning.

In addition to this, interpretation has also been further developed through the process of writing and re-writing. With the large sample size involved this has often been an arduous process in deciding what text to draw attention to and which to eliminate from presentation. Indeed, Gadamer himself when asked if he found pleasure in writing replied,

> *"No, it is violence. It is torture. Dialogue is fine. Even an interview! But writing for me is always an enormous self torture." (Gadamer as cited by Lawn, 2006, p.27).*

Although this appears amusing and even encouraging to every qualitative researcher during the process of writing, Gadamer loved the practical nature of dialogue and devoted much of his earlier life teaching where the process of conversation was rich and very apparent. Yet he also knew that writing allowed his process of thinking to be shared. It is only through the cognitive process of writing and committing understanding further to text that the interpretation deepens. Morse (1994) has summarised the cognitive process inherent in qualitative research believing that all qualitative analysis regardless of specific approach involves four phases of cognition. The first is the comprehending of the phenomenon specific to the study. The second relates to synthesising the phenomenon according to relations and links with other aspects. Thirdly, theorising is used about how and why relations appear and finally recontextualising is the final cognitive process. Here the researcher puts the

knowledge gained about the phenomena with relevant linkages into the context of evolving knowledge. On reflection, in this study, cognitive stage one and two have been more evident through the process of analysis utilising IPA and using the MAX-QDA package to structure relations into the themes and additional themes arrived at (see Table 8.1, overleaf). The cognitive processes of theorising and recontextualising for me have evidenced through the process of writing. Using all of these intellectual processes means that raw data can be considered, examined and reformulated to become a research product (Thorne 2000).

8.3 Determining service change

The main drivers from the findings in Phase 1 were to provide a service that could be responsive to the overarching themes identified in which expectation, uncertainty and personal understanding were prominent throughout the pathway. From Phase 1, the nurse specialist was seen as a welcome companion (Section 2.1.2) in the pathway who had a central role in facilitating aspects of service delivery to help manage expectation and to help individuals and their families live with this uncertainty. The findings from both phases have totalled thirty-two patient experiences, with twenty-four patients having had liver resection and eight patients not able to proceed to liver resection.

When considered in its entirety, this has equated to a substantial number of participants for a qualitative study and has not surprisingly, yielded an extensive quantity of data. As already stated, the major focus of the study, as outlined in Chapter 5 and revisited in Chapter 7, has been to establish change through a service intervention. Sections 8.3 to 8.7 will focus on the service change by examining the three intervention areas, (1) a structured nurse specialist telephone service (2) implementation of leaflet series for CRC liver metastases and (3) development of the buddy service, whilst the remainder of the chapter confirms the results from Phase 1 through the application of concepts in Gadamer's practical hermeneutics. As was the case in Chapter 6 and the earlier section of this chapter, participants responses are blended with health professional responses on appropriate sections rather than looked at in isolation. This continues to complement the methodology of hermeneutic phenomenology and in particular the concept of Gadamer's fusion of horizons drawn upon in this study.

Master theme	Super-ordinate theme	Sub-ordinate themes
1. A path of expectation: an enduring horizon	1.1 Travelling with the backdrop of diagnosis	1.1.1 Transitioning the diagnosis: from the well to the not so well 1.1.2 Confronting a doubly shocking diagnosis 1.1.3 Questioning in the context of 'me'
	1.2 Hoping for chances: desiring life, desiring time	1.2.1 Looking forward to possibilities in medicine 1.2.2. Acknowledging: There is no choice 1.2.3 Treating with curative intent means an active wait
2. The companion of uncertainty: a unified horizon	2.1 Health professionals: guardians of the CRLM pathway	2.1.1 Oncology: a place of safe keeping 2.1.2 Nurse specialists: a welcome companion
	2.2 Reliable information: a remedy for uncertainty	2.2.1 Struggles of communication give way to fear 2.2.2 Language has a memory 2.2.3 Uncertainty: a forever friend
3. A journey of personal understanding: an individual horizon	3.1 Unintended journeys	3.1.1 Understanding looks forward 3.1.2 Gratitude gives back
	3.2 Arriving	3.2.1 What matters most 3.2.2 Keeping hope alive

Table 8.1 Reference to themes Phase 1

8.4 Systematic telephone model

To reiterate, the telephone service aimed to have a minimum of three key in depth contacts with patients (see Chapter 7, Figure 7.4) or four contacts if patients had chemotherapy prior surgery. The reality as evidenced from a patient database maintained as part of routine nursing service, was that these calls were carried out ensuring that patients were having an in-depth assessment of how decisions and treatment was affecting them but in addition on average a further eight contacts were also maintained by phone and a further six in person at clinics. This was accomplished by the use of the SWIFT tool (Appendix X). When liver metastases were suspected, and a nurse specialist had initiated contact with that patient,

the process to a decision made about liver resectability was often lengthy, in part due to optimising the liver for surgery. It was also explained that with their consent, the nurse specialist would maintain contact at key decision points and have undertaken more in-depth phone calls at these times to try to reduce the impact of this wait in their lives. While there was no key 'script' for this introduction of the telephone support, the key concepts of telephone contact, managing the wait, assessing the individual and ensuring access to nurse specialist were highlighted in a memo of support. This was left to each nurse specialist to provide this information, delivering it in their own style and blending it with the, often sensitive, situation of diagnosis. It was important that the information was not given in a prescriptive way but adapted to each context. The mention of the SWIFT tool was not explained for this reason. Once again, these concepts were revisited again during the first phone call. Due to the nature of the impact of either a synchronous or metachronous presentation of liver metastases, it was expected that patients would not retain all aspects of telephone support, as is often demonstrated in the literature in clinical consultations (Kessels 2003, Nguyen 2019 et al).

8.4.1 Valuing the telephone contact as a natural

From the participants interviewed it was clear that the majority valued the systematic nature of phone contact, with 14 participants mentioning the idea of key contact at regular intervals. There seemed to be no doubt that patients had grasped the idea that a nurse specialist from the specific cancer team would be in regular contact and would feedback specific information discussed at the MDM at appropriate time points.

> *"It was explained right at the beginning that (x) would ring and I was full of praise for that as I had not had experience of hospitals before. My recollection was the days when the Professor was god-like and everybody sat back and waited, whereas if you are getting a balanced input you should get a better outcome" (Charles)*

This quotation suggests that some of the historical context of how information was exchanged had changed so that the power balance of decision making had transformed for the better. The input from different experts at the MDM was welcomed as care became more complex and ensured that decisions were given with the input of a range of experts. This participant's wife also drew on their previous family experience of obtaining information in a cancer diagnosis.

"Well, my parents had cancer and the difference was night and day. The care was all so fragmented, if a condition worsened, there was no one available and all the time you felt you'd fallen between the cracks. If you did speak to someone, they would say, that's not our area. It was on the relations to try to pull the thing together. It was like walking in glue." (Charles' wife)

This is similarly captured in Cook et al's (2019) paper when multidisciplinary members of a gynaecology oncology team described their nurse specialist role as "glue for our team" (p7). The experience of others also conveyed how good it was to have someone there to bridge the gap between different areas of care.

"I can't say how good it was to have the phone calls. I had known up front she would phone at different times, but she was also there for a number of things. You could phone and ask about literally anything or check an appointment. It was like having a PA for cancer". (Lisa)

and

"I had a feeling I was being very much guided through the process. I knew where I was standing, that I was beginning quite a long journey" (Ann, no op.)

and

"Contact with x (CNS) was great. It definitely helped me get through this time. I knew she was going to keep in touch at various points. Even my husband, if he could see something stressing me out, he would say, 'I phoned x today', so he felt comfortable giving x a ring". (Lindsey, no op.)

The wide range of role was also appreciated and the sense that the nurse specialist was also there for other family members. This could lead participants to say that they felt well supported and understood the role that the CNS had so much so that it became part of the natural. These particular patients had nothing to compare it to from a previous pathway, apart from their connotations about different eras or family experience of cancer. This shows how much previous experience and what Gadamer calls forestructure is present when individuals come to an experience for themselves.

The involvement of the CNS also encouraged individuals that something was happening during periods of active waiting as this individual, who was not able to proceed to liver resection, conveys.

"She was keeping in touch with what was happening and she had regular contact on the phone to let you know what the next move would be. It gave me confidence that they were actually doing something about it which was excellent" (Daniel, no op.)

The data itself is also affirming of the role of the CNS in general and of the importance of the relationship that is built over time. This is especially the case as for many being considered for liver resection can take place over a number of months.

"It is essential to have someone in that role, to oversee and look out for you. I don't think that communication would work well if that role didn't exist" (Ruth)

and

"It's been really good, someone to contact when you don't want to contact doctors (Lindsey)

and

"She built a relationship with me and got to know me and knew how much information she could give me over the phone and knows that's the kind of person I am that I want to have that information. It's an essential relationship" (Ruth)

As the wife of one participant points out, having someone outside of the family but with their own knowledge of the condition is helpful due to the amount of shielding that individuals take on to protect others in the family.

"People are being brave for each other and they need someone to talk over the reality with, to have someone to look at and say I'm really scared" (Wife of Charles)

8.4.2 Two axes of contact; access and presence

The development of the concept of 'presence' in contemporary nursing can be attributed to the work of Patricia Benner (Benner, 1984). She coined the verb "presencing" as one of the eight competencies of the helping role of the nurse. The findings have shown different levels of presence that the CNS has. This was mainly done in two ways, by ensuring that access was encouraged by telephone contact and by an actual physical presence at consultations or clinic dates.

In addition to the structured telephone support there was also the knowledge that people could contact the CNS.

"My CNS made sure that I knew that I could contact her at any time. I mean, I think, its' brilliant." (Karen)

This provided reassurance and would suggest that this individual certainly felt it worthwhile to contact. In other situations, the CNS was contacted to fill in missing gaps.

"When the path didn't move, I rang x [CNS]). The expectation of management has been so good but I was left in no doubt that I could also call" (Ann, no op)

Similarly, there was evidence that patients knew that when at the liver unit, the CNS could be contacted even though she was not able to be present at liver MDMs and consultations.

"There's continuity with the one person who has a knowledge of your background rather than you having to go start at base one each time, so you can get in contact when at the liver unit." (Wife of Charles)

On one occasion, a participant was alarmed when she missed a call and was left wondering if it was the CNS team.

"There were supportive phone calls all the way through but someone phoned me on Friday and I didn't get them and I worried about it all weekend." (Susan)

This may or may not have been the team as normally the team would leave a message but it characterises the importance of the calls to individuals. Rather than creating a dependency culture, the calls normally alleviated anxiety by keeping individuals informed. Only one participant preferred not to make contact on the phone as he wanted limited information but did express that he had allowed his wife to make contact and take calls.

"My wife has spoken to x [CNS] and been kept to date. I don't like to talk about how I'm getting on. I'm one of these people if people keep phoning me, I'll not heed it, like double glazing salesman." (Kenneth, no op)

This particular participant's informational style was respected although it was clear that his wife did benefit from the contact. Had there been no family who were keen for contact, this participant's information preference would have been respected but the key contacts to pass on information updates would have been maintained. Had someone declined being kept in touch using telephone contact, then appointments would be arranged at consultant clinics to pass on information. This participant was alone in feeling like this. A similar sentiment was also uncovered by this participant when considering patient information. Without probing

further, which was not possible to do so in this interview, it was difficult to tell whether this participant was utilising denial as an effective or ineffective method of dealing with the reality of what was happening. Certainly, much information is passed on in the current healthcare system via the medium of phone, helping to speed up information giving, prepare patients in advance regarding care and increase efficiency of appointments or treatments. It is difficult in this climate not to incorporate the use of the telephone and indeed there is much scope to incorporate additional technology in patient communication and assessment.

The additional aspect of contact was through being with individuals and their families at clinic consultations as the following quotations demonstrate.

> *"It's good to have somebody who knows what's going on because sometimes you see different people all the time. She was on the phone but also would come and see us at the clinic" (Judith)*

and

> *"She [CNS] has kept in touch all the way through until now. She rang to make sure I knew what was going on, and discussed what had been discussed at the regular meeting they had. She would say the next step is, or your case was discussed but we need further information or we are waiting to hear from the liver side or whatever the need was. In fact I saw her yesterday when I was here yesterday." (Diane)*

and

> *"Sometimes she would be in the consultation, I don't know how it was sometimes not, perhaps due to what was being said or if she was free, but it was great that she would be there and that you could come out and there was another sort of checking and verifying your understanding of what had been said to you, because there's an incredible amount of information to take in and a lot of white noise." (Wife of Archie)*

This verifying aspect of the CNS role after the consultation was helpful in processing information given during the consultations. The sense that patients were better prepared for clinics was also captured by both oncologists present at the focus group with one voicing the following.

> *"My suspicion is that patients are probably better informed of the uncertainties whey they come to clinic, they know there are various options being discussed rather than coming to discuss a definite plan. I think that's my sense, that there has been some progress there" (Oncologist no.1)*

While the colorectal surgeon did welcome the support model, they did not see the full extent of the revised support since their input was often prior to much of the support offered.

> *"Normally we see the patient in clinic and then are referring on so we don't necessarily see them for a while so we probably don't see that much of a difference in our clinic setting" (CRC surgeon)*

Much of the support work was hidden from the colorectal surgical colleagues, mainly being understood in the context of the oncology and liver setting. Indeed, much of the contact is by way of phone so is often hidden from what is seen by other clinical team colleagues.

8.4.3 A holistic sense of care

It was the intention of the SWIFT tool to guide conversation and ensure holistic assessment around by including the following areas in discussion, stress and coping, work/home life, illness, family/friends and things I like to do (see Chapter 7 section 3.1 and Appendix X). The aim of the tool was not to feel like it was a tick box exercise so that with skilled communication techniques adopted by the CNS, the use of the tool would feel more like a conversation. Having already established in section 8.4.1 that the telephone support was successful in relaying information at critical time points in the pathway, it was important to assess if patients felt a sense of holistic care about what was important to them in terms of their life cycle stage and additional commitments and priorities. Analysis of data relating to this area found this to be the case. One participant reflected,

> *"Looking back, it was good the way she did it. She found out you had understood the information and it taken it on board. She was concerned about everyone in the house, the kids and my husband. She would often say 'how does x [husband] feel about things, especially if I had difficult news" (Lindsey)*

This conveyed how this patient was able to reflect, in hindsight on how they were encouraged to process the information given at the time and how the emphasis on care was for all concerned in the family. This demonstrated the use of the SWIFT tool, specifically relating to the section on family/friends and reflected the ethos of the Family Systems Illness model as discussed in Chapter 7 section 2.1. The participant in hindsight saw how honesty and the need to keep communication open was facilitated by the CNS among relevant family members who were also impacted in her diagnosis. Judith recalled how her CNS had spent

time talking to their brother and sister to put their mind at rest. A further participant also expressed this,

"She didn't just look out for me but looked at everything, the whole family and how we were coping". (Ann, no op.)

This participant had previously experienced sudden infant death syndrome as an older mother and now had a young child. The sense of their experienced loss as a couple was great and this understandably fed into their concerns about Ann proceeding to liver resection.

Attention was also extended to issues of work also as one participant recounted.

"She was interested in all aspects of how cancer affected us, and how I was getting on returning to work with managing family life" (Ruth)

Here this participant was able to comment on how well supported she felt amid returning to work while balancing young family life. This holistic sense of care went beyond the illness alone as shown in section 8 as the CNS nursing belief echoed Wright et al's (1996) sentiment that illness is a family affair.

Being able to pinpoint potential issues of stress and help to identify coping strategies was also realised.

"x (CNS) has been absolutely tremendous. She phones me and my partner back and forth to see how we're doing. She understands and she gets to the bottom of what's bothering me. She's really fabulous. Although she wasn't working with the other hospital, she was keeping us informed." (Mark)

While the conveying of information concerned with liver resection was maintained, this participant also valued the fact that the CNS was able to extract out the emotional concerns when perhaps the participant did not fully realise what these were. This may come from the foreknowledge of the liver resection pathway on the CNS part and also the combination of the CNS's ability to use advanced communication skills to assess each patient individually. As such, this quotation also shows that they were aware the CNS was bridging the gap between the liver unit and the referring hospital. This in itself was reassuring since this was part of the original intention of the study. Patients appeared to feel that they were treated personally throughout a complex process.

"My CNS kept in touch and said that anytime she was at the end of the phone. It made me think somebody is caring, you're not just a number going through a conveyor belt." (Michael)

Overall there was the sense that the telephone support enabled individuals to talk about the cancer.

"Cancer is such a big scary word which has been the bogie man let out of the cupboard you know. The fact is that if you have problems you want to speak to someone about it who is involved in your treatment. It takes a lot of the stress away. It's been good to have the telephone support to do this." (Archie)

The combination of the CNS knowing the reality of the disease and building a relationship with the patients allowed individuals to speak more openly when perhaps they could not always do so to others closer to them. Other participants had reiterated this understanding also, knowing that the support they had provided had been central to helping them through this period, with one saying,

"Oh I doubt I would be here if it wasn't for them (CNS team). To be honest, I can't get over them, they were fantastic. They looked at all aspects of how the cancer affected me." (Hamish)

It appears that the SWIFT tool enabled the CNSs to ensure a holistic approach to patient assessment surrounding illness, friends and family, work, stress and coping and patient priorities. Discussion at the focus group found the tool to be particularly useful by the CNS who used the tool and carried out the majority of the telephone assessments.

"The tool is also straight forward without being prescriptive. It helps to explore information with the patient whilst building a good picture of their home and health situation." (Colorectal CNS no.1)

and

"There was always the fear that we had missed something before and were maybe taking different approaches. This way the tool standardises and formalises what we need to know and ask. It does help the telephone support with patients as it starts to establish the relationship we have with patients. I hope this in turn means that they can feel more comfortable and open in further contacts we have with them". (Colorectal CNS no.2)

In addition, there was also the recognition that using a standardised tool was beneficial for new members coming into the team in order to give a structure and prompts for more complex patient assessment. Both CNSs voiced this with one adding,

> *"It has been very helpful* having a specific tool that we can all use so that we are all covering the same relevant issues with patients. This is especially pertinent when we have new staff coming into the team" (Colorectal CNS no.2)

8.4.4 Attributes valued by patients

While not the intent of the study, it was apparent that the supportive contact provided through the structured telephone model and through presence at clinics, highlighted certain attributes of the nurse specialists involved which were valuable to patients and their families. Looking at these in more detail enabled me to see that these enhanced and gave further value to the telephone intervention.

Listening was recognised as a significant process that was active in nature. This was bound up with the concept of access in section 4.2 of this chapter and as highlighted in the following quotation.

> *"For a kick-off, she listens to you, she does listen and she's got that calming way of talking to you. You phone her anytime. I phoned her at the back of six one night and she phoned back" (Judith)*

This quotation highlights several insights, Firstly, through listening the CNS helped to bring calm to a period of uncertainty experienced through consideration for liver resection. This listening involves entering into the world of another and trying to understand a frame of reference different from their own, which forms the basis of hermeneutic listening (Kimball & Garrison 1996). The CNS listens to that individual understanding that they go through their unique experience but they also listen with a sense of fore-knowledge having known the pathway as experienced by others. One participant noted that the CNS had an attentiveness which was low key and not intrusive which complemented how the CNS listened. Secondly, the tone of voice being mentioned to as 'calming' also added to gaining a sense of control over a situation that is out with each individual's overall control. In fact, the tone of voice was also mentioned by others,

> *"She had a positive voice and gave positive messages despite being plunged into a very uncertain world" (Ann, (no op.))*

and

"She is a very clear speaker and is not a fast speaker so you can take it all in, which is ideal when they are trying to explain it to you" (Timothy, no op.)

These extracts highlight the importance of tone and clarity in speaking that help to take some of the franticness away from the individual health experience. This leads into the concept of containment. While uncertainty keeps possibility open, it cannot provide confinement to a situation. Lack of containment can lead to a sense of overwhelming. It is the foreknowledge that a CNS has developed from her experience with the pathway, that helps to contain the events for the individual. Finally, the first quotation also highlighted the accessibility beyond normal working hours in that the CNS was often ringing later than expected. Two other participants had also commented on this level of dedication, noting that they were often surprised that the CNS returned a call out of working hours.

While attentiveness towards the needs of the participants is a valued attribute of the CNS role, it can come at a price for the CNS. The nature of workload may mean that it is not so easily contained for the CNS within the boundaries of normal working hours. This additionally is a consideration on how the CNS ensures the emotional nature of involvement and workload is kept in balance in order to prevent against workplace burnout.

Familiarity was also identified an important feature which was only possible through ongoing relationship with the CNS. This ability to put at ease was an important part of getting to know the CNS but it also was important for trust as the relationship continued. One participant noted,

"It's as if you knew her all your life" (Lisa)

Several participants had known their CNS since their primary bowel surgery and this sense of knowing made them feel secure that the CNS would help them address future issues as they had experience of them having done so before.

Finally, the language used to describe the CNSs revealed them to have an enabling role which was valued. This enabling worked both ways, in seeking to help patients directly with concerns but also in enabling individuals to live well during the process of waiting. Two nouns were used by one participant and his wife revealing the enabling nature of the CNS.

"You know, she was like a little butterfly settling on his shoulder, really"
(Wife of Charles)

and

"She was like the glue to the whole thing" (Charles)

Both of these words powerfully describe the value of the CNS role. The use of the word 'butterfly' was used to describe the CNS being present at times when needed and the noun 'glue' suggests an element that helps a process cohere together. Other participants spoke of being 'carried along' (Diane) or of having a 'comforting presence' (Janice) all the way through. These attributes mentioned seemed to contribute to the telephone model and contact being of additional benefit to the patients who were being considered for liver resection.

Overall, there was a good level of evidence that the use of the telephone model worked with individuals who were hopefully looking forward to liver resection. This could be cross referenced with sub-ordinate theme 1.2.1 - looking forward to the possibilities in medicine. There was also evidence that they could deliver reliable information to provide more certainty which could be cross referenced with super-ordinate theme 2.2 – reliable information: a remedy for uncertainty and with helping to deal with treatment, related sub-ordinate theme, 1.2.3 – treating with curative intent means an active wait. The CNS acted as a companion throughout this period and a holistic or integrative approach also allowed individuals to understand their health situation in line with personal situations. This was in line with theme 3 – a journey of personal understanding; an individual horizon in which sub themes of understanding looks forward (3.1.1) what matters most (3.2.1) and keeping hope alive (3.2.2) were most pertinent.

8.5 The leaflet series

The development and patient review of the liver metastases leaflet series is detailed in Chapter 7 section 4. It was well received. All patients who proceeded to liver resection were given the three leaflets throughout the duration of being considered for liver surgery. The second and third one, about surgery and recovery respectively, were only given to patients for whom a certain decision had been made about liver surgery. For this reason, the four who did not proceed to liver resection only received the first leaflet, explaining the process of being considered for CRLM resection. Only two participants did not recall seeing any of them. These were both individuals who did not proceed to liver resection. The reasons for this was cited due to personal information style although he did understand that his wife had taken

the first leaflet and read it (Kenneth, no op.). The second could not remember getting the first leaflet as he always knew his position in getting to liver resection was not secure, saying,

"I'm not aware of it. I may have got it but maybe I didn't because it was uncertain I was getting the liver operation." (Timothy, no op.)

There were only two participants who were ambivalent about the purpose that the leaflets played for them for different reasons. The first had felt that she knew most of the information from the oncology and surgical consultations. The leaflets were designed to complement the consultations and in particular the first one was designed as a bridging gap before the initial liver consultation. There was one thing that she did learn from the leaflets that she could not recall learning elsewhere, commenting,

"I do remember reading in the leaflet that the surgery could be cancelled if there was an emergency and I thought that would be awful, but most things were explained to me either in consultation or over the phone so I didn't pay a lot of attention to the leaflets." (Karen)

This was a key item that was gleaned from the interviews with participants in Phase 1 of the study whereby better preparation that cancellation for liver surgery was necessary for liver transplants. The other participant who did not find benefit in the first leaflet was directly related to his preferred method of delivering information. He was not able to proceed to liver resection. He was aware of the uncertainty over getting to liver resection and hence he adopted a more cautious approach in taking on too much information in case it unnecessarily had an unhelpful effect.

"Yes, but I had been quite reticent about the liver that I didn't take too much from the leaflet. I was taking it a stage at a time" (Kenneth, no op.)

8.5.1 Written information and the reinforcing of expectations

Feedback from the nursing representation during the focus group commented on how useful it was to have the leaflet series and how patients had commented on their value.

"a high number of patients commented on the written information and they do find them really helpful" (Colorectal CNS no.2)

The first leaflet aimed to set out what was entailed in the consideration and workup to possible liver surgery. The information in this liver leaflet, in particular, was welcomed and clearly remembered as the following comments suggest.

"The first liver op leaflet was really helpful because it sets out the process of what is involved" (Lisa)

"I thought the leaflets were excellent. They were very good, they covered everything and made me realise what the whole process was about." (Ruth)

"Yes, I remember the leaflets. They were useful, especially the first one which told you about the workup." (Wife of Charles)

"I got the leaflets and they were helpful, my CNS gave or posted to me at different times, one about what would happen, the surgery and the recovery" (Michael)

The quotations emphasise how the first leaflet conveyed the totality of the process involved in arriving at a decision for liver resection and gave the sense that this was not a quick decision. The words used, 'process' and 'workup' suggest that often a number of elements have to come together and knowing this was helpful in reinforcing expectations already set out verbally through consultations or via telephone contact. This written information helps to layer up this concept of process and also acts to provide continuity across the service as evidenced by the following participant.

"Everything happened exactly as it said in the first leaflet. I came away from the liver consultation and thought, everything was discussed like the leaflet said." (Michael)

This aspect of preparation was encouraging. Where there is potentially so much information to take on board across the pathway then relying on verbal information alone from a consultation may not be sufficient. This also touches on the ability of written information to marry up information from different health professionals encountered. That could be done for those participants and also their families who may not have been present at consultations. The above quotation from Charles' wife highlights how family were able to benefit from the information which was shared as does the following,

"I found the leaflets very clear. They helped my daughter understand what was going on too." (Archie)

This has a benefit in bringing in additional family members or relevant others to an understanding of the process and can therefore pick up on aspects that are easier to overlook by the patient due to the process of anxiety. This is similar to the calming effect of having a friend or family member in the clinic consultation as evidenced by Esther in Phase 1, who although she did not proceed to liver resection, the presence of her friend in the consultation

helped to allay fears and lead her to a more hopeful state of mind. Even if the overall end process was not one of liver resection for this early participant in Phase 1, the important aspect was keeping hope evident. The overall outcome of course, is only known as time passes. Additionally, having the leaflets made the process more concrete or real as one participant disclosed,

"The fact that they were there made me realise people go through this so that was encouraging." (Lindsey)

This was particularly in the face of seeking information online and either retrieving information that was not applicable or was focused on survival statistics which then became alarming. It may be that information that was locally relevant also made for a more reliable sense of trust. A number of previous participants in Phase 1 had voiced that it was hard to find reliable information that related specifically to their pathway. As is evident through this thesis, there is not one typical pathway to liver resection but providing local information about the pathway process between the two hospitals involved, surgery and recovery is likely to provide reassurance and a sense of confidence in local care teams.

8.5.2 Providing continuity with the CNS role

The information series had a complementary role to the CNS as described through 8.3 and as evidenced in Chapter 6, section 6 in Phase 1. The provision of the information series allowed the nurse specialist to work with material, adding information at appropriate timepoints in line with how events unfolded at timepoints in decision making.

"x [CNS] gave me these leaflets for when bowel cancer spreads to the liver, surgery and recovery. There were three of them and I got them at different times." (Mark)

and

"as well as keeping in touch, she sent me information, I got leaflets about liver surgery and bowel cancer, there's three leaflets. She would have sent me more information if I'd wanted." (Diane)

To do this ensured that the CNS was able to know at which points patients were in the pathways which is often time consuming. Working closely with the CNS in the liver unit also allowed for co-ordination of this but this may not always easy to do in the midst of other clinical commitments and as additional pathways for more complex treatment develop. As

seen in Chapter 6, oncology was seen as the place of safe keeping for patients who were receiving treatment (2.1.1) so having a presence at oncology clinics became an important aspect as evidenced in section 8.4. The MDM could still be used as a method of facilitating contact with patients but the additional contact could not be maintained through oncology clinics. It is for these patients particularly that access to CNS may be lacking.

Two patients commented on how the leaflets had addressed specific queries which had been beneficial to them.

> *"I asked a question, I can't remember what is was and x (CNS) answered it on the phone but she also sent me leaflets which again answered the very question I had asked but I thought, isn't that amazing you know, that she had taken note and posted the information out to me." (Susan)*

and

> *"I thought they were a lot of help, especially when it came to the mood swings, I didn't think I was doing that until I read it." (Charles)*

Susan seemed to pass surprise that the CNS would almost go out if her way by posting the leaflets suggests that the she did not realise that this was part of the normal course of events but that they were sent because of something relevant to them. The second participant reveals how information about potential low mood post-surgery helped to give a sense of authenticity to what he was himself experiencing. In turn this helped to broach discussion with his wife who had noticed but had found it difficult to bring up in conversation. The provision of information in the leaflet series enabled a large amount of information to be given and the reality is that some aspects might prove more relevant to others. The important aspect here was that the development of the series added further choice as to how information was received, by a method that complemented the CNS role. Feedback from the focus group, supported this advantage,

> *"I think the written information is incredible. I think ultimately it's part of the key to CNS continuity and support." (Oncologist no.2)*

8.5.3 Additional considerations

Only two people commented on additional information that would have been valued at the time of recovery post liver resection. The first commented on requiring further information on wound care and the second on requiring nutritional information to improve healing.

"I thought the leaflets were excellent. They were very good, they covered everything. The only thing would have been good was advice to keep wound dry because I struggled with the wound after discharge". (Ruth)

and

"I could have benefitted from more nutritional information post liver surgery when you consider how important food is for healing" (Karen)

Certainly, it was difficult to keep the information concise without becoming overwhelming to read. Key contact numbers for further information were provided by both CNS teams and encouraged to use.

Perhaps the most major consideration from feedback on the leaflets was based around the differing needs of people for information and prompts questions over how much we engage with individuals on their preferred method of information. One participant who valued the information would have preferred to have all three leaflets together.

"To say here is all the information, if you want it that's where you find it… some people do want to overload with information and it also allows choice but you don't have to read it." (Lisa)

The element of information choice is vital in allowing people to have control (Tran et al 2019) especially in circumstances that are beyond their control, yet this quotation is perceptive on behalf of the individual in that they know while they themselves have a high drive for information, others may feel overwhelmed by too much information rather than comforted or in control. In reality, choice may mean something very different to different people. It is also interesting, as it is given in hindsight when this participant had the liver resection. At the time the first leaflet was given, there was no knowledge that they would proceed to surgery. The decision was made at the time to only give the first leaflet out when patients were definitely considered for liver surgery. The other leaflets were only given if the decision was made to proceed to liver resection. Deciding not to give all the leaflets at one time was taken as a decision to protect patient emotions and raise an unrealistic sense of hope, with information that was not relevant at that time. It is here that the sense of pre-knowledge or forestructure comes into play as this particular patient was thinking of what may have been relevant for her without realising the complexity and diversity of patients on the pathway for liver resection. This participant was different from the other participants who did not mention wishing they had the leaflets at the same time. This may be explained by differing

information needs or may reflect the need of patients to take have a 'one step at a time' approach, realising that not all information may be relevant for them.

On the whole, the leaflets were welcomed by health professionals and patients alike. Their use helped to aid the CNS role in managing uncertainty and containing expectation and specifically in providing more trustworthy local information, than what might be harder to find online. This can be clearly cross referenced with super-ordinate theme 2.2 – reliable information: a remedy for uncertainty.

8.6 The buddy service

The implementation of the buddy service was set out in Chapter 7 in response to the findings in Phase 1 where over half of participants voiced they would have found it useful to speak to someone having gone through the same experience and seven participants offered to speak to someone in the future if it would be of any help. The main aim of the service was to connect people with similar experiences being considered for liver resection with those who had already had the resection. All the five buddies who had undergone training were disease free after resection and continued in follow-up. All 16 participants were offered a buddy early in the process of consideration and the leaflet series also reinforced the idea of the buddy service.

Perhaps one of the most surprising findings from the buddy intervention was that no one actually took up the offer of meeting with a buddy at any point in the process. This appears surprising given that half of the participants in Phase 1 had voiced a desire to do so believing it would have helped, particularly to alleviate the feeling of isolation experienced in that they felt they were the only ones going through the workup for CRLM resection. It is clear that there is much to learn from this and that the process of reflection or what we commonly refer to as hindsight, varies hugely from going through the process of consideration for liver resection in real time. The reasons for this and future applications for consideration are explored further in Chapter 9. For now, reviewing some of the reasons why the buddy service was not taken up, may be helpful in understanding the lack of engagement.

Two participants could not recall being offered a buddy. It is both fascinating and important as health professionals to realise how memory and a priority of recall operates for different patients who will all receive the same information. At the time of receiving information, participants may have a common understanding in its receipt but on recall may have different

opinions of what information was shared. Both of these participants did not proceed to liver resection (Kenneth and Greg) and therefore did not receive all the liver leaflet series, which helped to reinforce the buddy service. Both had recounted not engaging with the first leaflet as there was too much uncertainty over their particular route to surgery, preferring to be guided by medical staff. Both of their responses mirrored the two types of responses that were reflected in the group as a whole, those very definitely opposed to meeting a buddy and those who said they may consider it again. The first stated that even if he had remembered being offered it, would not have helped.

"No, on a personal basis, no. It's just the way I do things. Just the way I've been brought up, still upper lip and all that. It wouldn't help me." (Kenneth, no op.)

The second participant, on hearing it was a possibility, did not rule out the possibility that it might be useful in the future, while at the same time remaining non-committal about the need to do so.

"I wasn't sure it was offered. I just kind of get on with it but I might consider that one, I could again." (Timothy, no op.)

Curiously, he also added at the end of his interview, that if he could be of any help to anyone in the future from his experience, then to get back in touch. There seemed to be a genuine willingness to help others and give back something, as evidenced in the Phase 1 participants but a reluctance to interact with others as the receiver of information.

8.6.1 Fear of negativity

There were a further ten people who were clear they would not have found contact useful, with fear of carrying forward negativity, being rated amongst the reasons.

"I think some people aren't as positive as I like to be in this situation and I didn't need that". (Lisa)

"It was one of those things I was aware of and I thought do I need to know about someone else's experience and I thought, I don't think so." (Archie)

"I didn't want to take on other people's concerns." (Hamish)

"I could have spoken to another patient, but then again, I thought if knew what was ahead, I'm better not knowing." (Judith)

There was a personal awareness among these participants of the uncertainty in the pathway for them as individuals and taking on the journey that someone else had with their own set of particular concerns may have led to more negative thinking. If anything from Phase 1 and Phase 2 the need to maintain hope was paramount in working through the process of consideration and managing the wait for liver surgery that patients could not afford to imbibe possible negativity. This could be understandably overwhelming and restrictive in how individuals encountered each step in the way. The quotation from Judith, highlights this step by step approach of not reading too far into the future, certainly an approach that has been utilised in the support offered by the CNS team and during the telephone intervention. Interestingly, three of these participants were among others to offer to help to speak to other patients if needed in the future. Perhaps those who offer to buddy think they will be good because of their experience but at the time of their own experience they were not convinced that anyone will be able to speak appropriately to their situation.

8.6.2 Personal experiences of negativity

One patient was clear that he did not want to be put in contact with a buddy due to a previous encounter with a patient during his primary surgery. He had complex pelvic surgery involving removal of bowel primary and formation of urostomy and ileostomy. At the time he remembers being keen to speak to someone else before the surgery since his surgery and the impact on his life was to be so radical. He remembers organising this through his nurse specialist but the conversation did not benefit him. He recounts,

> *"I phoned up him and he was all doom and gloom and he said 'maybe we can meet up for a cup of tea.' I said 'maybe I'll ring you back,' but after that I had no intention of meeting. I was all doom and gloom. It was the down side of it all. I was wanting someone to be a wee bit more perky about it all. He depressed me. I thought I'll have to delete his number." (Mark)*

This rather amusingly told situation, unpacks a lot of important detail about patient one to one support. The participant rang the previous patient at a time that was convenient, giving them control of a situation that could involve some anxiety. His focus and desire was on hearing a positive story that while this was life changing surgery, the previous patient was regaining normality and mastering life. The reality the participant heard was very different so much so that he had to skilfully extract himself from the conversation, having shut down the possibility of further meeting in his head, while being polite at the same time. The

conversation was so negative that he felt he could not maintain contact. This experience meant that the participant did not want to meet a buddy again, fearing carrying yet more negativity into a situation that required a brighter or more 'perky' outlook.

> "After that, I wasn't wanting to speak to anyone who didn't know what they were talking about from a health professional so I just kept in touch with x [CNS]" (Mark)

For this reason, maintaining support with his CNS (who incidentally was the same CNS he had contact with for his primary surgery) was important to him and being guided by the medical team. The professional support who were able to draw from a range of observed experiences was deemed more supportive and affirming.

8.6.3 Too many variations in experiences

For others, the idea that an experience from another patient could fit into their own experience was seen as unlikely, as there were too many variations in the process leading to liver resection.

> *"It's very much an individual consideration, for me it wasn't high on the list. One of the things that has become clearer is how individual people are, treatment has to be customised to you because you could react in a completely different way from the person who has just had it before. Whilst it is helpful to be aware of somebody else's experience, its not necessarily relevant because there are so many permutations out there that could come together" (Ruth)*

and

> *"No, not for me, I can understand why other people would want to but I can only talk about my experience and that involves breast cancer too. For me talking to someone else would not have been helpful." (Diane)*

Ruth benefited from the targeted therapy Cetuximab (only suitable with k-Ras wild-type mutation) and was aware that her pathway to resection was likely to be different from many others. The advert of targeted therapies and tailoring individual plans does mean that pathways are often different for patients with the same cancer type and as outlined in Chapter 2, there are many presentations of both synchronous and metachronous liver metastases, complicating pathways further. Diane felt that her previous breast cancer could not be extrapolated out from her colorectal experience and that both were unique to her, that the one could not be considered without the other. Perhaps in this situation, she may

have felt that she was putting the additional burden of computing another cancer onto someone else and that this may not have been helpful.

8.6.3 Family and friends' support

The last finding that prevented individuals from making contact with a buddy was the security that individuals felt within their own family and friendship circle. Whilst it is recognised that not everyone has such social networks or equally wants to have support from existing networks, the source of family and peer support has already been evidenced earlier in this chapter and in Chapter 6. Two individuals cited family directly with providing adequate support.

> *"I didn't consider meeting someone else. To be honest, I have good family and friend support. That was enough for me. I have a good relationship with my family." (Ruth)*

and

> *"The truth was when I went to the hospital, I just wanted to get back home. I could imagine, if I didn't get to my allotment and wasn't able to walk my dog, I could imagine meeting with others so I could speak to someone" (Susan)*

The last participant reveals how much the things of home bring comfort and normality, a stark constant with time spent at the hospital. For those who have undergone primary surgery and then develop a metachronous liver metastases during follow-up, there can seem no break to hospital consultations and imaging, interrupting the normality of life. Interestingly, this participant thought that meeting others, "sounded like something for comfort and diversion", while distinctively, she mentioned activities that she did alone provided her with the comfort and diversion that she needed. Comfort and diversion in themselves form a necessary part in maintaining the normality of life for individuals and hence in maintaining hope. What might be comforting and divertive for one individual may not be the case for another. This is especially important when considering introducing the concept of the patient buddy.

8.6.4 The notion of 'on reflection' and 'hindsight'

The remainder of participants on reflection considered that it may have been something that could have been helpful although it appeared that they could not consider it at the time or certainly not before the surgery.

"Maybe I should have met someone but I think I had too much to think about. I just wanted to have my treatment" *(Michael)*

The words from this participant, who later went on to the buddy group evening four months post liver surgery, reveal how all-consuming the process of having surgery was. It was too overwhelming to think about meeting others. The fact that when a further opportunity was offered to meet as part of a group, she accepted, showed how the interest to do so was there but the timing had to be right either to meet individually or in a group. A further participant also echoed this sentiment of time being an important factor.

"I could not take it on as there wasn't time to process meeting someone but in hindsight, I think I would have benefitted from meeting with someone afterwards. There are a lot of things that you're not sure about because you've never experienced it so you don't know what is normal. It would be good to see now how people are getting on." (Karen)

My dual role as both researcher and professional insider, meant that I felt I needed to mention this to the nurse specialist team so that further opportunities to explore potential support should still be offered. The participant consented to me doing so but in the end decided not to take it further. What matters here is access to options and choice not particular uptake. It also highlights the contemplative nature of hindsight. Voicing 'it might have been helpful' or 'I could have' is very different to actively seeking out that support when offered. The following quotations show this from two participants who voiced a contemplative nebulousness about what they could have done but didn't.

"It may have been helpful, but I didn't at the time. I just want at the time to know that I hadn't fallen out of things" (Janice)

and

"I did meet people in chemo unit, we were going through maybe not same thing but similar so I was happy with that level. Maybe it would have been useful to speak to someone who was in a very similar situation…" (Ann, no op.)

Kenneth who was not able to proceed with an operation, found adequate levels of support from other cancer patients during treatment times, a similar concept to networks in section 8.13.3. He also revealed that,

"I think it would have helped to have spoken to someone who had gone through a similar experience but I think I was partly in denial and if I spoke to someone, well that's quite a big step." (Kenneth, no op.)

Taking formal steps to voice what is happening can be frightening and is a part of a dual narrative that is often evident in individuals whose illness is palliative, a concept that is discussed in Chapter 9.

8.6.5 Buddy group evening, Maggie's Centre

While it was recognised that a buddy meeting in a group setting was not part of the original intervention, it does represent an interesting diversification of the intended one to one buddy system. All of the twelve participants in Phase 2 who had undergone liver resection were invited to take attend the evening by their nurse specialist. Of these potential twelve, five had shown interest but on the evening two were able to attend, one with their spouse. Four of the original trained buddies were able to attend the evening. Two of the participants and one spouse picked up on the impact of the evening during the patient interviews. The overall sense of the evening was one of encouragement. However, it highlighted a dualistic aspect of the concept of a buddy, indicated in the previous section, exposing both encouraging and jarring emotions.

The security of the environment and the company of the others in attendance allowed for participants to feel safe as evidenced by the following words.

"It was encouraging to meet other people who had the liver surgery many years ago. It felt a safe place to ask questions*." (Michael)*

and

"The evening was very useful. I think the fact that we all had this commonality of the same cancer it was good to have this discussion and share our experiences. I don't think I could have handled it before. I was full of questions before." (Archie)

All buddy representatives had met each other before during the buddy training so knew of each other's particular cancer story. At the time, all of them remained in follow-up from liver resection. This in itself was seen as encouraging by the participants equating this with no current disease recurrence. Archie's wife also stated,

"It was good to see everyone looking so well" (Wife of Archie)

Looking healthy was seen as a hopeful sign of recovery and moving on from the process of liver surgery. Although, this is interesting in itself, because it is known that even with the presence of metastatic disease, individuals can look very well and culturally we can tend to place much emphasis on equating appearance with health. This is something which is evidenced from patients whom I meet with outside of this study, frequently commenting about the frustrations of receiving well-meaning comments from family and friends about how well they look when in reality their life may be very limited.

An important aspect of this meeting together was the function of safety, with one participant commenting,

> *"There were about six of us and I was the youngest and I thought, they all seem older but we've all had the same kind of cancer. It was interesting because I could talk and say what I felt and how I went to pieces" (Michael)*

Despite being somewhat younger than the other group members, it could be seen that cancer acts as levelling the playing field. What unified them was, the same cancer and that everyone had shared an experience relating to this cancer type. Another aspect of this unifying was that it provided safety in being able to reflect back through the worst of emotions and share them. This is something which both earlier in this chapter and in Chapter 6 was apparent that could be difficult to do with family. In some ways, there was no one to hurt and protect in this situation, unlike the complex protective mechanisms that can often make it difficult for family to open with.

The one nurse specialist who attended this buddy evening had also commented in the focus group, where she saw encouraging interactions from those in attendance.

> *"For myself, as a nurse specialist, going to the buddy support meeting at Maggie's helped me see how isolated patients feel at times. It was a real eye opener to sit with them. The whole study is working to give the correct information, in the right amount at the right time, helping to make a big difference to how individuals then carry on with everything else that happens." (Colorectal CNS)*

It helped to hear about isolation at first hand. This was particularly the case, when the team have often been sceptical of buddy interactions which was driven from an over paternalistic sense of how to protect patients if they had negative encounters with another patient.

Yet despite this, the concept of jarring emotions which are often unexpected do arise, which denotes something of the dualistic nature of the benefit of such groups with one participant being struck that he had learnt that one of the patient buddies had liver surgery three times. This was something which he returned to during the interview which showed how difficult it was to clear this aspect from his thinking.

> *"I thought it was a very good thing. The only thing I found scary was the guy sitting next to me on my right, had surgery three times. You know when somebody says something and this explosion goes off in your head and you think boy, what did I hear, three times!" (Archie)*

To hear this did cause jarring emotions and raised the possibility again of recurrence. At no time, did he mention that there was any positive message attached to each time the disease was removed, which a different individual may have picked up on. To face recurrence and three liver resections was almost something he could not get past perhaps because this was the first time he had learned it was possible and he had implied that going through the liver resection once had been an ordeal the first time. He later voiced that hearing it made him think he couldn't go through the liver resection again. Interestingly, his wife did not hear 'three times' and did not pick up on any of the negativity that can sometimes happen from group interaction. It may be that while being aware of it at the time, that she did not recall it as she took hope from the possibility of further resections or that she genuinely did not hear during the group. Perhaps seeing those who had gone before in the same operation and were still alive was positively colouring how she took on information that night. This clearly demonstrates how being in the same room and hearing different things can occur. One participated through the knowledge and reference point of being a patient and the other through the support of a family member. Any potential recurrence or possible liver resections would ask for different things from each involved.

Meeting with others can be valuable to maintain hope but equally it can destroy hope, something which when considering liver resection, participants have felt is critical to maintain. Overall, the use of the buddy and buddy support evening as in intervention in this study has raised more questions as to how and when we use this external peer model of support. This is further explored in Chapter 9. The existence of the buddy service, whether accessed or not, allowed for an element of choice of interaction. This was especially important in treatment where there was no overall choice of management (sub-ordinate theme 1.2.2 – acknowledging: there is no choice). For those who did encounter the

individuals acting as buddies at the patient evening, there was evidence that the context of knowing a similar situation allowed for exploration of the diagnosis. This was relevant to super-ordinate theme 1.1 – travelling with the backdrop of diagnosis. Equally this was relevant to the major theme number 3 – a journey of personal understanding: an individual horizon. Interestingly and again, as in Phase 1, a number of participants offered to meet with others going the same situation if that would be helpful. This reflected the sense of gratitude for having undergone liver resection or being well to want to give back which was identified in sub-ordinate theme 3.1.2 – gratitude gives back.

8.7 Additional gaps in service; closing the loop

Part of the commitment to determining change, is also identifying further gaps as the service evolves and pulling out aspects where further change could improve. This is especially important in pathways which are prone to change due to being responsive as new ideas and research emerge about how best to treat the disease. This is also reflective of the study methodology chosen and the role that Gadamer's fusion of horizons has played in the study. Closing the hermeneutic circle of learning is ongoing in that the evaluation can yield further aspects that were not part of the original aim of the study but yet are crucial to the patient experience. The following aspects were identified that had particular bearing for patients across the spectrum of being considered for liver resection; early intervention from the nurse specialist team, expansion of the role of the CNS at the liver site, correspondence of consultations and the structure of the MDM.

8.7.1 Early intervention from the nurse specialist team

One aspect that arose highlighted a process that could be improved early on in the process of diagnosis. This was trying to bridge the communication silence between investigation and seeing the initial consultant surgeon, especially after colonoscopy and during staging investigations. Although as health professionals, we may not strictly see this related to the liver resection process, on reflection for four participants it was all wrapped up in the overall diagnosis. This was the case for these four participants who were also diagnosed with synchronous liver metastases as these quotations demonstrate from two participants.

> *"It was three or four weeks before I saw him [consultant] so it was actually extremely quick and I know it was extremely quick but the problem was that I did not know anything, nobody had told me anything at this point." (Ruth)*

and

"It's like a lifetime, one day is a lifetime at that point when you are waiting, so I know in retrospect it was dealt with very quickly but it didn't, it feet like it." (Judith)

and

"for example if the nurse comes into play earlier, who could literally say, or somebody, somebody just say, you're not going to hear anything else until after the scan." (Lisa)

As expounded in chapter 6, waiting was a prominent feature of being considered for liver resection. Seeing the difference that a nurse specialist could make throughout this process meant that individuals could see that early contact by a nurse specialist in the initial period of waiting for confirmation of diagnosis could also be beneficial. Early contact can prove challenging without confirmation of histology at risk of wrongly confirming a diagnosis but perhaps there is an earlier role to be deployed here which may help to set out expectations of the initial wait to management plan, particularly when endoscopic investigation suggests a cancer. Additionally, earlier contact would also mean adequate resourcing to set aside time to make earlier introductions across all referring sites.

8.7.2 Expansion of CNS role at liver site

For some, the development of the liver CNS would have been welcomed, especially those who had a more complex pathway to liver resection or those who had difficulty post-operatively like the following participant, who experienced post-operative pain.

"I would have liked the equivalent of the colorectal nurse at the RIE. I would have found that really helpful. Probably she is overworked but it wasn't easy to get her" (Lisa)

The reason the colorectal CNS team primarily carried out the intervention described in Chapter 7 was due to the different evolution of the role of the liver CNS and the realisation that they would not be able to do this due to time allocation with other aspects of the role. In some ways, the colorectal CNS team bridged the gap. Since the study was undertaken further resource allocation has been made for an additional role within the liver team. This may mean that additional support may be developed for patients on the liver resection pathway. This is particularly applicable when some patients feel like the liver team are waiting in the wings and there is no name or contact of those involved as Lisa also indicated.

"I would have preferred to have some contact with the liver people or at least to be saying this is the person we are dealing with because it was all a bit like the 'the liver people.'" (Lisa)

This echoed some of the experiences from Phase 1 whereby for some, not meeting or having contact with the liver team until after treatment was too long away. Developing the liver CNS role for early contact may help to alleviate this concern for some people.

8.7.3 Correspondence following consultations

The documentation of information for patients following consultations which would help to reinforce proposed treatment plans and rationale. This could be a copy of a letter sent to the GP but it would outline key information gone over in the consultation.

"This might be time and effort, I suppose, but if after a consultation things were written down, you know you would get the same letter from your oncologist or surgeon that your GP gets, that would be helpful. I would like to have a copy of that. Sometimes when you are in a clinic, you are trying to listen and then trying to think what to ask, it would be reasonable to get a copy because we are all entitled to see our notes" (Karen)

From the words of the above participant, this seems to stem from two reasons; firstly to consolidate the information discussed as it can be difficult to remember the volume of information discussed and secondly from a patient sense of entitlement, since the information relates directly to them. As early as 2000, the British Government had set out as part of the The NHS Plan (DoH 2000) that patients should receive a copy of any health professional correspondence to another health professional. While in Scotland, the revised Charter of Patients' Rights and Responsibilities (Scot. Govt. 2019) states that

"I have the right to see my personal information that is held by NHS Scotland. I can do this by making a 'subject access request' (verbally or in writing) to my local health board or GP practice, and I should receive a response within a month. It does not usually cost anything to make a subject access request (Scottish Government 2019, p.17)".

However, it does not specify or suggest that patients should automatically receive a copy of their consultation. Indeed, there is a move that all out-patient letters and discharge summaries that are currently written to GPS and copied to patients should be revised and written directly to patients with a copy to the GP, as stated by Raynor et al (2018). This would put the patient back at the centre of their care and rather as an aside and it forms the basis of recent guidelines developed by the Academy of Medical Royal Colleges (2018) in writing

letters to patients. Furthermore, a number of pilot studies, also run within the same locality as this study have gone further in audio recording consultations with colorectal, breast and prostate as a way of increasing patient decision making, reducing uncertainty and regret in decision making (Hacking et al 2013, Shepherd et al 2018). Certainly, incorporating letters to patients would seem a good starting ground as a means of building on both the telephone model and the leaflet series and as a way of re-balancing the relationship between patients and health professionals as was the original intention stated in the early 2000s (Eaton 2002).

8.7.4 Structural issues within the MDM

For some, experiencing difficulties with timely communication from the MDM was a result of structural issues. Many patients are now well familiar with the role of MDMs from charity and hospital websites so that they expect to know when they are held. The co-ordinating role of the oncology team, meant that information was fed back from the liver MDM.

> *"It all came through the oncologist, saying the liver people have been able to look at your case or it wasn't discussed this week. I didn't find that very satisfactory. Are they looking at it or not? I just wanted to know the facts". (Lisa)*

and

> *"It was all a bit vague, it was almost like a bit second hand, a bit triple hand" (Lisa)*

When this information did not come through or was not discussed for whatever reason, it was here where frustration sets in and the potential for trust can break down. The idea of triple hand information conveys this. Discussion from the focus group showed that the health professionals were all too aware of this possibility and that looking at options such as changing the discussion order of patients to allow the liver team to attend the colorectal MDM or teleconferencing were discussed. Such structural aspects can make huge difference to patient experience.

8.8 Returning to hermeneutics; a further inspection

The use of hermeneutic phenomenology as a methodology in this study has also allowed further layers of interpretation to come to the surface during analysis of the findings from Phase 2. It can be seen from preceding sections, that concepts of expectation, uncertainty and understanding were also evident in Phase 2. Correctly, the focus required to that of determining service change but the findings also validate those from Phase 1. To present

Phase 2 results under the same headings as Phase 1 would be difficult within the restrictions of this thesis but by utilising Gadamerian hermeneutics, it can be seen that similar themes emerge. This is a novel way not only to engage with Gadamerian philosophy to show understanding and applicability of Gadamerian methodology, but also to demonstrate that Phase 2 results confirm the results of Phase 1.

The themes of expectation, uncertainty and understanding are applicable to key concepts as outlined in Gadamer's *Truth and Method* (2013): being, authenticity, pre-conception (forestructure), historicity and temporality. Gadamer's philosophical hermeneutics has been well suited to the practical element of the study design as suggested in section 8 and having undertaken the analysis these key concepts are seen to be reflected in the findings, showing particular pertinence to this study. Among other notable concepts discussed in *Truth and Method* (Gadamer, 2013), these concepts, Gadamer suggested are critical when reading, understanding and interpreting text. Regan (2012) emphasises this by writing,

> *"What makes these concepts significant is the central interpretative relationship of the researcher within the qualitative research process."*
> *(Regan 2012 p. 287)*

Through the active process of analysis, a greater awareness of these concepts has been made known. To conclude this chapter, each of these concepts will be briefly considered in turn, thus returning to and emphasising the experiential findings of the nature of the CRLM in Phase 1 with Phase 2, which may not have related to the revised support pathway itself. It is here the ontological focus of philosophical hermeneutics can be valued. Gadamer (2013) held that it is only through language that we can know experience. As Regan writes, the Kantian meaning of phenomenon was "that which shows itself in itself" as discoursed by Heidegger (Regan, 2012, p.287). In this study, language was known through the discourse of interviews and focus groups. The dialogue between interviewer and interviewee was the way in which new phenomena were made known. The spoken and later written word, captured in the transcripts and now this thesis have helped to make elements of the CRLM pathway known. Understanding takes a method suitable to it and engaging with philosophical hermeneutics has been the means to this. Gadamer recognised that the old ways of positivism based in natural science were not conducive at getting to the soul of human experience. One of problems of natural science was that it eliminated the observer. In this study recognition of my position of researcher with insider knowledge of the colorectal pathway was also central to the concept of interpretation and a fused horizon. This study

did not shy away from this but echoed the sentiment of Gadamer that in order to understand we always bring something to the interpretation (Gadamer 2013).

8.8.1 Being

The concept of 'Being' (Dasein) is expounded by Heidegger in his magnus opus, in 1962, Being and Time (Heidegger, 2010). Gadamer takes up tenets of this concept in hermeneutic phenomenology. Being makes language possible. By being in the world, we are aware of the world around us and immersed in it, sharing that world with others (Alweiss 2002). Without question, the subject area of this thesis is pertinent to human existence. It is also manifests a sharing of experience, of which Gadamer's sense of 'Being' incorporates. Participants have shared this pathway with others who have travelled it before but while there may be shared aspects, their experience remains unique to them. A path of expectation: an enduring horizon was keenly felt among participants in Phase 2, as in Phase 1 with participants clearly understanding that while there were no guarantees that a liver resection would mean no future recurrence, it was the only possible way of cure or extending life in what would be palliative situation.

"Psychologically, here's me thinking, Oh God, I don't want to die or you know, I feel like running away with what's happening to me" (Susan)

and

"It was a very sobering time. I'm not sure that it was an option for you to say, I don't think I'll have the chemotherapy, I will go straight to the surgery" (Wife of Charles)

In this way, participants understanding of their predicament was wrapped up with their diagnosis and also the understanding that in order to pursue possible cure, there was no choice but to proceed to liver resection. It could also extend to their families as shown by Charles's wife. The preciousness of being was understood so that the pursuit of continuing 'to be' was a path they needed to travel.

8.8.2 Authenticity

This concept is developed from Heidegger's thinking. Heidegger believed that authenticity is being true to oneself but this was at the exclusion of the community surrounding that individual (Regan 2012). In contrast, Gadamer acknowledges the interplay of others to the individual. There is always a context to how a situation affects us and consequently others around us. (Gadamer 2013). Being an authentic being means not only operating in relation to considering self but considering how others influence our thinking past or present (Regan

2012). For Gadamer, we must also be open in order to genuinely understand and be authentic. Throughout the process of interviewing and on reading the transcripts I had no reason to believe that participants were not being open. Rather, there was a sense of candor and frankness, often revealing deeply personal aspects of how the diagnosis of liver metastasis affected them and others. For me, looking on, the participants were revealing their authenticity of experience. The rawness of emotion captured in words and often emotional reflection, revealed this. The often emotional or heartfelt responses resonated with similar findings in Phase 1 showing that while improvements were beneficial, they would never diminish the uncertainty of their diagnosis and potential treatment.

> *"The fact that I didn't have any symptoms, I was completely shocked that it had spread to another part of my body. I was really, really shocked. I was with my sister at the time and she could see I was devastated." (Ruth)*

This itself is realistic and provides authenticity in the findings, relating back to the sub-ordinate theme of *'Confronting a doubly shocking diagnosis'*. While it is difficult to select examples of this authenticity above other examples, there are some that stand out, that again resonate with Phase 1. Such an example of this real emotion is considering the personal pain that one had experienced with experiencing cancer in the family before,

> *"It brought everything back to him" (Wife of Hamish)*

Hamish's first wife had died as a result of breast cancer and he had cared for her throughout treatment and in her final days at home. In some these words are also tied up with the concept of 'historicity' in Section 8.15, but the fact that his world had been so connected with another who had experienced cancer, shows the interplay of lives. As such this information could not be withheld during interview.

Another interesting example is from Daniel who was not able to undergo liver resection despite treatment workup. He recalls how as the result of a consultation, his girlfriend had picked up more of the reality that his liver may not be operable.

> *"My girlfriend said, 'maybe you're borderline. I thought I don't want to borderline." (Daniel)*

This word 'borderline' which was so bruising to Julia in Phase 1 who could also not undergo liver resection, made Daniel also 'kneejerk'. It was an immediate heartfelt reaction that made him want to continue to pursue liver resection until deemed otherwise.

Treatment related examples of authenticity that resonated with Phase 1 were an acknowledgement of low mood or irritability with others during treatment, with five participants expressing this as especially bad through chemotherapy. In addition, there was an acknowledgement by eight participants that they felt the liver surgery to be more of an ordeal than bowel surgery with Archie saying,

"I felt like I'd been hit by a truck," (Archie)

The use of such words bring him right back to the experience of liver surgery, even though he was recounting it over a year later. The ability to bring back a memory demonstrates the vividness and reality of the experience.

Finally, experiencing such a distinct health experience has implications for recovery. This finding was also evident in Phase 1 in the theme, '*A journey of personal understanding: an individual horizon'*, under the sub-ordinate theme of '*keeping hope alive*.' Quotations from Hamish and Karen below highlight this.

"We're going to have a 'to do' list and we're gonna do this and that. We won't look back." (Hamish)

and

"I'm looking after myself now. I'm taking time out for myself." (Karen)

Being able to undergo liver resection allowed participants to look to the future, not being blind to the possibility that the further recurrence might happen but because of a renewed appreciation of time that had been given.

8.8.3 Pre-conception

Pre-conception or forestructure as Gadamer often referred this to, is most keenly to be implied to the interpreter of the text or diaglogue. This relates to anything pre-existing within the mind of the interpreter that may inaccurately flavour the text itself. Citing Heidegger, he writes that this should be the *'first, last and constant task'* of the hermeneutic method (Gadamer 2013 p.279). There should be a continual working out in the mind of the interpreter whether they are interpreting the text with the structure that they have imposed upon it or whether they interpret using what they know to resonate with the text. We must refrain from trying to project meaning as soon as an initial meaning appears in the text but rather work backward and forward between any wrongly pre-conceived ideas in order to let the text speak for itself. As Gadamer conveys,

"This constant process of new projection constitutes the movement of understanding and interpretation." (Gadamer, 2013 p.280)

For myself as researcher with previous insider knowledge of the CRLM pathway, examining my thoughts as I approached the text for any wrongly placed interpretation took ongoing discipline. However, as seen in Chapter 5, the position of the interpreter was not to discounted but rather valued. In this way what has been experienced before gives the interpreter a working hypothesis from which to further develop understanding (Regan 2012).

In addition to my own pre-conceptions, there was also an awareness that pre-conceptions about colorectal liver metastases were being challenged.

"We're pushing the envelope more and more, we're potentially giving more options to those with borderline disease. It makes it difficult to say to patients, categorically, this is not going to happen." (Liver surgeon)

This pushing of the boundaries, as referred to at the outset in Chapter 2, challenges what is possible but at the same time means that it is not possible for everyone. What was clarified for me with my own pre-conceptions of the pathway, both from the participants and the focus group sessions was the real challenge of management that exists for those with unclear liver resectability. As one of the oncologists pointed out; for such patients it is not one discussion regarding getting to liver resection, it is many; between different departments, a period of treatment, imaging and rediscussion. Certainly, looking at other methods to improve a faster turnaround of review from the liver team would be warranted in the absence of a liver specialist being able to attend the MDM. This may prevent the experience of the following patient,

"The liver people weren't there this week and then my case wasn't discussed. I didn't find that satisfactory. I didn't care knowing one way or other if my case was going to be looked at but I wanted to know the facts." (Lisa)

8.8.4 Historicity

By our very nature we are historical beings. We are thrown into a world that has a historical context and this makes us a product of our history at any point in time. Gadamer saw that our sense of history becomes more clearly understood and often more appreciated the longer we are in time or as Dasein matures in time (Gadamer 2013). The nature of the family life cycle becomes relevant to this concept as there will be priorities and a different sense of historical context related to where we are in that life cycle (Rolland 2005). The fact that we

enter a world, without our choosing and into circumstances unavoidably not of our own making is especially relevant to how cancer can be viewed, displacing not only a sense of one's being but of one's world.

There are two areas that stand out in relation to historicity which are common to Phase 1 and Phase 2. The first relates to those understanding their current health situation in the context of genetic background. This is situated within the sub theme 'Questioning in the context of me', situated within 'A path of expectation: an enduring horizon'. Several participants had this on their thoughts as they approached the pathway.

"I only found out after my operation from my Mum, that my Dad had bowel cancer and my Grandpa died of that, died young too." (Greg)

and

"Mum's three brothers died of cancer. And I wondered if I'm taking that path." (Carol)

Greg's quotation is interesting as it hints at the possibility that his mother may have not told him about his family history until he was through the primary surgery. This may have been evidence of how that link to the past is so deep-seated that it can sometimes be hard to see ones own future in the context of it. Carol's words expand on this when she considers if she is facing the future of her uncles. This is difficult to set aside in her thinking before treatment has even begun because it may be that despite treatment her path is already established. It was as if Carol could see a number of paths laid out before her but she did not know which was hers. Only with the passing of time would this become clear.

The other area where a sense of history is apparent is by encountering a lack of or limited historical background. Once again there were no one who had knew anyone who had underwent this type of surgery before, although Mark did meet someone at chemotherapy who was also on the same pathway. The knowledge that is path did not have much of a history itself may also have been unnerving. Lisa recounted this when speaking with one of the surgical team,

"He said you know this is really hard to get your head around, if this had been 10-12 years ago we wouldn't be treating you" (Lisa)

Lisa remembered struggling with this idea in her thoughts at the time. The liver resection was only possible by advances in medicine. Her sense of gratitude, known only through a position

of hindsight, stemmed from this knowledge. It also echoed sentiments applicable to 'being' in that were her existence not to have been within a certain period of time, then there may not have been the option to proceed to liver resection.

8.8.5 Temporality

Finally, the concept of temporality has an important bearing on interpretation. For Gadamer, the transient nature of speech means that when a message is revealed it also resonates within temporal understanding (Gadamer 2013). That is only when it fades into the past, can true meaning be acknowledged. That is not to say that present dialogue cannot have meaning but it may also deepen with time, both for the one imparting the words and the interpreter.

Working with transcripts in this study has helped to capture the essence of the spoken word at a precise time of participants' thinking. Having the opportunity to present the findings orally and through committing the findings to paper in this thesis have been a study of interpretation over time. Gadamer suggests that unlike contemporary ideas of memory recall that were being debated at the time, the passage of time deepens understanding and the idea of 'temporal distance,' can provide a sense of objectivity when feelings associated with an experience becomes more distant (Gadamer 2013). The remainder quotations from those who could not undergo liver surgery emphasise this.

> *"I realise now when the* liver surgeons couldn't operate, there wasn't much I could do. I couldn't fix it myself." *(Greg, no op.)*

> *"I never appreciated quite how much they were going to take away, three quarters and so I realise it was quite a serious operation." (Daniel, no op.)*

> *"It's taken for granted that scans can do a lot more than they can. It's not until something happens like this until you realise they can't." (Kenneth, no op.)*

This ability of hindsight was a feature present in Phase 1 in both the main themes of 'The companion of uncertainty: a unified horizon and 'A journey of personal revelation: an individual horizon. One of the areas where I could clearly see the value of temporality in interpretation was in grappling with apparently conflicting statements. For example, for Greg, (who could not undergo liver resection), he declared near the start of the interview that,

> *"I know that I can't have the liver resection." (Greg, no. op.)*

Sometime later in the interview, he also declares,

> *"I don't mind if they want to go back and take a chunk at a time, take it all in a oner or take a chunk and wait until the liver grows back." (Greg, no op.)*

During the interview, these words jarred with me as a researcher, finding it difficult to reconcile that this participant knew a liver resection was not possible. A similar situation occurred in Phase 1 and it is through the lens of temporality that this was actually an expression of hope in the context of something that was not possible. This is further discussed in Chapter 9.

For patients going the CRLM pathway, each stage in that pathway can feel like it can last a lifetime but with time it moves onto another phase. The pictorial image at the beginning of this thesis depicting the snail climbing Mount Fiji and in conjunction with Isso's poem, appears to show each stage in the climb going on forever until a new horizon is met. The nature of each stage of the CRLM pathway is set within the context of a health situation that makes one realise of the very temporality of life.

8.9 Chapter summary

For Gadamer, the truth is always coming into being as we adapt our view according to information through the fusion of horizons (Gadamer 1964). However, this study has been more than an effort to understand. This chapter has presented the response to that renewed understanding detailed in Chapter 6 and is reflective of the practical element to the study, committed to utilising the data and driving forward a service revision to support patients being considered for colorectal liver metastases resection. The findings have shown that the implementation of a telephone assessment model and leaflet series have been well received but that uptake with an individual patient buddy had not been accepted. The use of hermeneutic phenomenology in this study has worked on two levels. It has viewed language as a set of words with a message but it has also exposed a reality for those on the CRLM pathway. Using Gadamer's fusion of horizons has allowed for the merging of not only the service revision in Chapter 7 but also the interpretation of the data gathered and presented in this chapter. This work has further implications for practice, especially how we work with patients' sense of hope to contain expectations and manage uncertainty. These thoughts will be presented in the final chapter.

Chapter 9

Paths with expectancy, stories of hope: reflections on learning from a fusion of horizons

"Man cannot live without hope; that is the only proposition which I would gladly continue to defend without qualification." (Gadamer 2002, as cited by Grodin (2004)

9.1 Chapter overview

To date this thesis has sought to uncover the experiences of patients who are considered for colorectal liver resection and in response, present the findings of a model of support for this patient population. The study was conducted in two phases with an interim period of service development placed in between. There was limited relevant literature to endorse the chosen model (as discussed in Chapter 3) therefore the model of support was solely driven from the data in Phase 1 (Chapter 6). Fundamentally, this thesis has allowed individuals to tell their stories of an experience unique to them, but through analysis it was also evident that those stories held components of similar shared experiences with others. While the stories centred around the pathway and treatment towards possible liver resection, the experiences did more than capture experiences about that pathway and service. What was powerful, was that individually and collectively, these were stories of hope, embedded within an onco-surgical context of evolving practice. To conclude this thesis, this chapter will look back at the journey, the methodology, the power of the patient story and the contribution of this study to existing research in this setting. It will discuss the related concepts of the medicalisation of mortality and realistic medicine, and the need for a new conceptualisation of metastatic disease before raising some considerations as to how we might, as health professionals, give shape to hope in this pathway. The chapter will close by considering the study limitations and recommendations.

9.2 Reflecting on the journey

This study arose from the sense of unease around the lack of support for patients being considered for colorectal liver metastases resection, as identified by the colorectal nurse specialist team. It was clear from the outset that managing both the practical and emotional burden of this pathway was difficult for patients and families alike and that this often appeared to be intensified with the involvement of two different hospital sites. This study has attempted not only to investigate how that pathway was experienced but also to address

some of the lack of support for this patient population. This has meant that it has been a study of two distinct parts. Phase 1 gathered and analysed the responses of 16 patients and a health professional focus group. In response, an interim period allowed for the development of a support model, primarily led by the colorectal cancer nursing team. This period involved the development of a telephone assessment service, a series of patient literature and a patient buddy service. Phase 2 encompassed an evaluation of this newly implemented support model by conducting, in the same method as with the first Phase, further interviews with 16 patients and a health professional focus group in order to determine the value of that overall intervention.

This thesis has presented the journey, beginning by setting in context the treatment of colorectal liver metastases in Chapter 2, before considering the relevant patient experience literature pertaining to this study in Chapter 3 and examining further the role of hope as a response to managing uncertainty in Chapter 4. Chapter 5 detailed the chosen methodology of hermeneutic phenomenology as central to the study with the use of Interpretive Phenomenological Analysis (IPA). The findings of Phase 1 were set out in Chapter 6 and to follow chronologically, Chapter 7 discussed the interim phase where the new supportive model was presented. It then returned to discuss the findings of Phase 2. Overall the study yielded findings from each phase. In Phase 1 the experiences were captured under three master themes which were attached to three horizons of understanding,

- a path of expectation: an enduring horizon
- the companion of uncertainty: a unified horizon
- a journey of personal understanding: an individual horizon

The development of the revision of support by way of telephone model, development of leaflet series and patient buddy group all sought to confront and equip in dealing with the difficulties of expectation management and uncertainty and to augment personal understanding. With the exception of the patient buddy service, the support model was welcomed and while additional support could never eliminate uncertainty, it was shown to alleviate the burden of uncertainty.

When viewed in a paragraph, the journey of this study seems easily reducible, but the reality has been an immersive journey for me as researcher, as I have sought to do justice to the experiences of those patients with the aim of developing a service. I am aware that I had the

privilege of being trusted with their stories and learning through listening about their own personal journeys.

Without the willingness of these patients to share their story of this time in their lives, there would have been a significant delay in improving this area of support and the result would have been informed by only health professionals, giving a very unilateral viewpoint. In addition, the work has been applicable to other areas of practice and has had implications for the separation of the colorectal nursing service into primary and secondary teams (Section 9.12). It has been a strength of the study that it has been informed by patients and health professionals and the underpinning structure of Gadamer's 'fusion of horizons' (Gadamer 2013) has given a beneficial focus in drawing together differing patient experiences, with health professional experiences and my interpretation as both insider health professional and outsider in a researcher capacity. There has been a demonstration of fusion on multiple levels. The journey has been significant as it is the second study to examine the experiences of patients being considered for CRLM and the first to use a pure patient sample and then use these experiences to implement a service change. Considering this, the patients' stories have given this study its potency in allowing both the singular and collective patient voice to be heard.

9.3 The appropriateness of methodology

Chapter Five detailed the rationale for how the study was conducted and the use of hermeneutic phenomenology. After completion of the study the appropriateness of the methodology was realised from a different vantage point. Traditionally, healthcare has focused on presentation of signs, symptoms and treatment. While this has been correct, it has tended to focus on the how of healthcare but has left little to the 'who' in healthcare and how being on the receipt of care affects individuals. Chapter Three contended that with the advent of greater technical possibilities in medicine operating across different disciplines, there is a greater likelihood of supporting pathways to such care becoming more complex. This is evident within the CRLM, due to the presentation of disease, changeability of that disease and involvement of different disciplines, as outlined in Chapter Two. As health professionals, complex pathways hold an unknown entity for us and if we are to be truly patient-centred, we must ask ourselves what is it like to experience such a complex pathway? How do individuals experience such emerging treatment when the context of treatment is placed within the reality of secondary disease? Is there anything that we can do, to make

such pathways easier? As Buckley et al (2016) write, any progression in illness by its nature, causes individuals to respond differently because of the absence of health.

> *"As their illness develops, they are compelled to move to a different path, walk along a different life-map and re-navigate as they respond and adapt to a changing health status." (Buckley et al 2016)*

As health professionals we look on to this path yet we are more than onlookers. Inherently, in this study, the involvement of the nurse specialists action of implementing a support model has shown that they are committed to help individuals re-navigate life and make living a priority in the midst of an uncertain health situation. They do this from a different vantage point, having the realisation of a number of possible outcomes for outcomes for patients. When we attain a new horizon we gain the breadth of vision that a person who is trying to understand must have (Gadamer, 2013). This is the benefit of our vantage as health professionals; breadth of vision. This position is difficult to obtain when going through the pathway as a patient. This process may involve setting aside preconceptions for both health professional and patient so that each moves beyond their own individual understanding to a more universal understanding together. This part and a whole framework is critical to the nurse specialists as they work alongside individuals, understanding each part of the CRLM pathway and also the whole in the context of the colorectal cancer diagnosis.

The appropriateness of using Gadamerian philosophy has helped to realise that 'part' and the 'whole concept of understanding. This has occurred on three levels. The first level is the acknowledgement of the segments of experience that individuals themselves see but that all of the experience can only be fully appreciated from a distance when the chaos of the situation fades away. The second is the weaving of the experiences of individuals and the understanding of the health professionals, the individuals representing only part of the understanding required in order to comprehend the CRLM, with the health professionals adding a wider lens of experience which stems from knowledge of the disease and knowledge of routes or deters that the pathway may yield along the way. The final level is that part and a whole experience which comes from my position as a researcher as I have sought to analyse the data as parts, merging those parts into the whole as findings. This is an analysis that recognises the interplay between past and present, whole and part. This understanding resounds with the words of Wilhem Dilthey, the hermeneutic philosopher who predates Gadamer,

"In understanding we start from the connection of the given, living whole, in order to make the past comprehensible in terms of it." (Dilthey as cited by Monk, 2004, p.44)

This was exemplified in that the interviews did not just contain clinical experiences about the pathway itself but the humanity of how their lives were affected at the time of diagnosis and during treatment and being considered for CRLM resection. The current is always flavoured by the past and the participant looks back in order to find meaning in their present.

The use of IPA as an analysis method also sought to draw out that experience. Pietkiewicz and Smith (2014) believed that studies incorporating the use of IPA should meet certain characteristics. They suggested that the aim and research questions should be to understand the individual, in-depth experience of a participant. Sampling should contain purposeful sampling and enlist a homogenous sample but smaller sample sizes are often adequate so as not to compromise depth. Methodology should involve participants being able to tell their stories in an unhindered way without placing additional structure on them. The analysis should identify descriptive and interpretative themes engaging the reader to see more of the lived experience of the subject group and the importance of the researcher's position should be noted through reflexivity in the study approach and analysis. With the exception of a smaller sample size, this study has met this criteria having a sample of patients from two phases who despite their entry into the CRLM pathway, they all had liver only metastases and were all being considered for liver resection. The total larger sample size was combined from both phases and was required due to the practical nature of assessing a change in service together with including a number of patients who did not proceed to liver resection. The semi-structured style of interviewing was used more as an aide memoire and facilitated their experience without little prompting. In addition, the place of the researcher with insider-outsider knowledge has been interwoven throughout the research.

Furthermore, due to the timescale of the pathway to play out, particularly in Phase 2, this was a study that was suited to a longer timeframe and hence suited the part-time nature of the researcher. The data collection could not have been carried out in a shorter timeframe. While the study had the practical emphasis of service improvement it was withheld that it was not action research (as outlined in Chapter 5) due to the focus on hermeneutic philosophy to capture experience of the CRLM pathway in both phases.

9.4 The significance of 'the story'

While I sought to understand patient experience in this patient population being considered for CRLM resection, I did not expect be surprised by the strength of the voice of the patient as storyteller. Collectively what bubbled up to the surface of analysis was that these accounts were stories of hope. The etymology of the word 'story' has its roots in the Middle English word 'storie' and Anglo-French 'estorie'. This is thought to be a combination with Old French, 'estoir' and Latin, 'historia'. Although the word has become widely used to mean anything from a personal account, to fictitious tale or anecdote, the historical context of the word helpfully conveys the sense that a personal story is rooted and holds some sense of history pertinent to the storyteller. The author Donald Miller writes,

> *"A story is based on what people think is important, so when we live a story, we are telling people around us what we think is important."*
> *(Miller 2009 p.125)*

While sadly, reports such as the Francis Inquiry (Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013) have revealed upsetting examples of poor-quality care, they have stressed the importance of giving a voice to the concerns and experiences of patients and their families. The revision of The Nursing and Midwifery Council's code of conduct (2015) accentuated the importance of working in association with patients. It makes it a requirement to "listen to people and respond to their preferences and concerns" (p.6) while being able to "work in partnership with people to make sure you deliver care effectively" (p.6). Searching out and listening to the story therefore sits within the culture and the requirements that we practice in. Buckely et al (2016) state that it becomes a responsibility to listen reflectively to patient stories and to consider their position within the patient–nurse relationship. From my position, it became a responsibility to not only listen but to act in response to those stories in order to improve future patient experiences.

Although this work has centred around the pathway and process to liver resection, the interviews have allowed patients to tell their stories from the advantage of a historical viewpoint. Primarily for all of those interviewed in both Phases, their end goal was to achieve CRLM resection, yet having that longer-term historical vantage to tell the story, has allowed what the process of being considered meant for them to be exposed at a certain time in their lives.

This concept of story lends itself well to Gadamer's hermeneutic phenomenology on two accounts. Firstly, the belief of historical perspective is important in Gadamerian phenomenology because the past forms part of the key to understanding the present. This can be clearly seen in Chapter 6, section 6.2 under the theme of *'A path of expectation; an enduring horizon'* and more specifically the super-ordinate theme (6.2.1) of *'Traveling with the background of diagnosis'*. None of what the participants shared could be understood without going back to the time of diagnosis and in fact there was a constant revisiting of the original diagnosis (whether diagnosed as synchronous or metachronous liver metastases in follow-up). Secondly, the concept that our traditions (also defined as our preconceptions) which are rooted in the past often collide with our present understanding to form a new understanding on a situation is particularly relevant. This means we cannot remove ourselves objectively from the past. The past is embedded in our horizon. The reality is we may not be conscious of preconceptions or aware how they can influence our present understanding. This is clearly punctuated through all of the themes uncovered through the findings. The first sits within the theme *'A path of expectation; an enduring horizon'*, under the sub-ordinate theme '*Questioning in the context of me'.* It has been apparent that an association or link with cancer either in the family or support network can influence patient understanding either positively or negatively when considering their own individual situation and this can often present a challenge to redirect to a different viewpoint. Difficulty in removing oneself objectively can also be seen in the sub-ordinate theme, 'looking forward to possibilities in medicine', when the possibility of what a patient might want to happen is not possible due to lack of understanding of what is technically possible or due to presence of disease which limits possibilities.

The second sits within the theme, *'The companion of uncertainty; a unified horizon',* with the sub-ordinate theme*, 'language has a memory'.* A struggle to let go of some unhelpful ways in which aspects of care were communicated or were perceived to have been communicated was very evident here.

The final sits within the theme, *'A journey of personal understanding; an individual horizon* under the sub-ordinate theme of *'understanding looks forward',* where it was acutely apparent that only on reflection was there a fuller understanding of what the whole pathway to liver resection entailed. This was very different to those health professionals interviewed through both focus groups who were able to hold that wider angled view of the overall

pathways, knowing both about the possible pitfalls in the pathway and also the disease process.

An additional benefit of capturing the story with a longer viewpoint was the unexpected benefit that it had to participants. The ease that participants came forward to participation, once approached, suggests not only the sense of gratitude that they wanted to take part but also the sense of importance to talk about something which mattered to them and in which they were a central protagonist. They knew their own script because it was their own experience. All eight participants in both Phases who did not proceed to liver resection were willing to come forward showing that it was not just the end point of liver resection which was relevant to them. Indeed, Callum (Phase 1) identified that had he not gone through the process his life would be in a very different place. Despite his immediate anger about not being able to go through the liver resection and having a period of trying to make sense of it all, he had been able to work out priorities in his life and voiced having a stronger repaired sense of relationships which were important to him. As health professionals learning from this is critically important. Firstly, while we do often get to develop relationships through time, we often see snapshots of people's lives. We do not see the whole story. Were we to see Callum at the time or in the weeks after it was conveyed that liver resection was not possible, we would have seen despair. At the time of interview, Callum had hope, yet the decision had been made several months before that he could not proceed to liver resection. He had revealed that had this diagnosis not happened, his life would not have been in the strength of place he now saw it. This example depicts the task of supporting individuals through this challenging pathway where the ebb and flow of hope is evident. The ancient pre-Socratic philosopher, Heraclitis (c.535 – c.475BC) is reputably to have said a similar sentiment,

> *"Everything flows and nothing abides; everything gives way and nothing stays fixed." (Heraclitis of Ephesus, as cited by Butler-Bowden 2013, para.9)*

Engaging with the CRLM pathway from a different horizon has allowed me to gain a greater sense of appreciation of the changeable nature of that pathway for individuals and consequently the fluidity of hope contained within it.

Furthermore, the use of the story in periods of ill-health or the derived term, illness narrative, is a way of an individual making sense of their experiences (Sulik 2010). As a medical

sociologist, Arthur Frank has been instrumental in developing the concept of illness narrative, set out through his influential book in 1995, 'The Wounded Storyteller: Body, Ilness and Ethics (2013). He was able to use his own cancer diagnosis and recovery to reflect upon the illness story which commonly follows a restitution, chaos, or quest pattern, weaving its way through the story. The restitution period signifies the belief or hope that this period is temporary and will be overcome. This can move into the chaos period where the illness is seen to get worse. This I can see is where uncertainty takes hold and hope fades into the distance. That may also happen because of an elongated treatment process which may not have the desired effect. Finally, the quest section of the story is where the experience of the illness can be used positively, and the individual might seek to transform oneself through overcoming adversity and re-learning what is important in life. I can the applicability of this pattern to the patient experiences in this study. Although I see the restitution period occurring after the shock of the diagnosis and that transitioning from the well to the not so well. Clearly the quest period echoes the third master theme of personal understanding but I would argue that it is not only gained by overcoming adversity but it may be gained through the process of adversity as those who did not proceed to liver resection showed.

This brings together the personal value of sharing an illness story and the suitable environment that the interviews provided in order to do so. Interestingly, Frank (2013) considers that the chaos narrative is generally told retrospectively as chaos itself is prohibitive to an individual in being able to tell a story. This is clearly evident through listening to the patterns of chaos in the collective stories. Reflection allows the distance to look with different eyes and indeed provides the time for another horizon to form for that individual through which they have reassessed their understanding of the situation. It also affords the benefit of control which Frank (2013) states is seen to be the opposite of chaos. Generally, control occurs when chaos ceases. Gaining that long-term view can only be achieved through time and having that opportunity to discuss their story with someone who they know is also familiar with their journey provides a therapeutic encounter (Morecroft et al 2010).

9.5 Contribution of this study to current knowledge

The contribution of this study is in relation to the overall intention of the study. The aim of the study was to use patient and health professionals' experiences of the colorectal liver metastases pathway to plan a support model for future patients and then to re-evaluate the

revised pathway by reassessing patient and health professionals' experiences. These aims were important due to the perceived gap, as identified by the specialist nursing team, in the support received for those being considered for colorectal liver metastases resection. The study questions therefore have direct relevance to future patients experiencing this pathway and to health professionals, helping them navigate the pathway. The study does three things in relation to furthering knowledge in the area of the patient experience of liver metastases and the management of uncertainty in patients by,

(1) adding to the body of phenomenological knowledge regarding patients being considered for colorectal liver resection
(2) demonstrating value of knowledge by incorporation of the model into clinical practice
(3) contributing to the implications of hope theory in surgically resectable metastastic disease

Firstly, it expanded on the findings of the three studies identified in Chapter 3 all of which presented a phenomenological account of patient experience of surgery for liver metastases. The only directly related study was that of McCahill & Hamel-Bissell (2009), with the Vidnes et al (2013) study incorporating the use of liver surgery, albeit liver transplant for liver metastases and an aspect of Whale's (2016) doctoral study featuring a phenomenological account within a quantitatively based quality of life study. These studies had valuable, but only partial, insights with limitations as detailed in Chapter 3, Section 3.2.1. They have not been able to provide the full picture of the pathway from diagnosis to a period after liver resection or the decision not to proceed to resection. This study adds to what might be known about the colorectal liver metastases pathway by viewing it along three horizons: patient expectation, uncertainty and personal understanding. Each horizon contains additional viewpoints that lie within it, allowing further insight into the pathway itself, as detailed in Chapter 5. These horizons serve an enriching purpose when considering other pathways of a complex nature to allow assessment of what measures could be considered to meet the support needs of the patient population associated with it.

Secondly, the model used in the study has been incorporated into clinical practice, providing a workable solution to gaps in support originally identified at the start of the study, whilst also determining its value after implementation. The learning gained from the lack of uptake from individuals to the buddy service is valuable in designing patient participation and shows

much potential in the possibiity of individuals meeting with similar individuals after they have been through a health event rather than before. The use of the SWIFT tool as detailed in Chapter 7, has also a purpose in other aspects of the specialist nursing team's clinical practice and has been shared for use within the department. To date there are no other published studies that have documented the use of the SWIFT tool. Furthermore, this study has affirmed the work of the nurse specialist in complex disease management. Furthermore, this study is original, in that at the time of writing, it is the only study recounting the use of phenomenology to drive forward a service change and then return to phenomenology to assess that change in the area of colorectal liver metastases resection. The study is not merely about a hermeneutic evaluation of experiences in order to enhance cancer care, in the area of colorectal liver metastases, but it is the only study demonstrating change as a result of phenomenological inquiry in this field. In this way it has reflected the part and the whole viewpoint that is integral to hermeneutics (Regan 2012).

Finally, this study contributes to the implications for the theory and application of hope within the potentially curative possibility of metastatic disease. It can be seen that aspects of Snyder's hope theory (2000) and Herth's work on hope (2000) are particularly germane. While Snyder's hope theory (2000) relating to goal attainment is more challenging to apply to the nature of cancer in general, as argued in Chapter 4, it can be seen that aspects of goal attainment, i.e. the goal of getting to the next stage in liver resection is still evident. However, this falls short when the obstacle of cancer cannot be overcome as hoped. This may be the case when further imaging upstages the disease from that previously understood and renders the patient inoperable for liver resection. However, it is evident from both Chapter 6 & 8 that hope is not lost but rather readjusted in those who did not proceed to liver resection. Herth's (2000) focus on hope takes into account the changing needs in the context of illness and of the significant role that it can play in terminal illness, shifting towards differing types of hope as curative aspirations translate into palliation and the reality of life limitation. Both Herth and Snyder view hope as a way to maintain personal motivation yet, perhaps the contribution of Snyder and Herth do not go far enough in relation to how hope is utilised by patients in the context of metastatic disease that still has the potential to be curative. Perhaps there needs to be a new way of conceptualising such metastatic disease that blends the contribution of both Snyder and Herth to date to generate a new understanding of hope in metastatic disease. This is further picked up in Section 9.8.

9.6 Resection of colorectal liver metastases; where does it sit within the 'medicalisation of mortality?'

The current situation with CRLM is the result of cumulative advances in medicine, notably technology in surgery and pharmacology in oncology. It has a comparable survival outcome with post-operative adjuvant chemotherapy and there is no doubt, where it not for these advances, we would not have seen the success in extension of life that we now see. At the same time a tension is evident, for the success stories are not all we see as this study has shown by use of a phenomenological exploration into the experiences of some of those being considered for CRLM. A perhaps more cynical look at the situation might conclude that CRLM for some might only be delaying the inevitable and that is death itself. It is worth pausing to consider if for some, CRLM might only be the medicalisation of mortality. Medicalisation can be viewed as "defining a problem in medical terms, usually as an illness or disorder, or using a medical intervention to treat it." Conrad (2005 p.3).

There may be a close connection to overdiagnosis but van Dijk et al (2016) are quick to point out that medicalisation is not by definition negative having seen some tremendous benefits in certain situations. Childbirth itself has seen huge outcomes in terms of live births by medicalisation, but negatively an increase in Caeserean section rates.

Medicalisation of mortality means that we have entrusted death to medicine but this does not mean that either one can be fixed (Gwande 2014). We now must learn to cope with the limits of our knowledge.

> *"We have no greater unfixables than ageing and death itself" (Gwande, Reith Lecture, Edinburgh, 2014b)*

Gwande (2014b) reflects that learning about mortality was not part of medical training. It was about how to fix people so much so that it did not equip medical staff to deal with death well, perhaps not only for their patients but also for themselves. Clark (2002) on speaking about medicalisation writes,

> *"The term has become synonymous with the sense of a profession reaching too far: into the body, the mind, and even the soul itself. Its use is now almost always pejorative, negative and antagonistic." (Clark 2002 p.905).*

Clark (2002) gives homage to Ivan Illich who developed his original assessment of medicalisation and in particular the medicalisation of the dying in which he claimed that

modern medicine had "brought the epoch of natural death to an end" (Illich 1976 in Clark 2002, p.905). There was a growing concern about how to improve end of life care on both sides of the Atlantic during the 1950s but by the time Illich was writing mid1970s, concern had grown about futile treatments with poor outcomes. Illich's critique of the medicalisation of dying encapsulated four main facets. Firstly, there was a loss of capacity to accept death and suffering as meaningful aspects of life. Secondly, there was a sense of being in a state of war against death at all stages of the life cycle. Thirdly, a crippling of personal and family care was evident with a devaluing of traditional rituals surrounding the dying. Instead this was replaced was an institutionalised form of caring for the dying which was often equated as less personal. Finally, there was a societal rejection of terminology associated with the dying or bereaved which often was associated with a negativity of as Illich referred to within his culture, a form of deviance. Following on from the 1950s, came a rise in the palliative care movement, notably acclaimed to Cicely Saunders, become a worthy inspiration and model to follow. Despite the growing movements in palliative care, Illich saw that the wider medical system continued to view death as something to be resisted, postponed or avoided (Clark 2002). Indeed, attacks were also made on the medicalisation of palliative care. In many ways medicine has always had the problem of balancing technical intervention with a personal humanistic approach to their dying patients. Today, this tension has deepened as options for extending life have grown. Although Clark was writing in the early 2000s, the sentiment of his interpretation on Illich is valid for today and particularly relevant for CRLM. Clark (2002) writes

> *"just that palliative care has encouraged medicine to be gentler in its acceptance of death, parallel developments in the medical system have redoubled efforts in the opposite direction" (Clark 2002, p.905).*

Yet the picture that we see of CRLM having an equivalent outcome of post-operative adjuvant outcome can in no way be equated with palliation. Somehow both the message of Illich and the message of hope need to balanced.

9.7 CRLM and its place in realistic medicine

At this point, the value of placing the CRLM pathway within the context of 'realistic medicine' is seen as referenced to in Chapter 1. The idea behind Realistic Medicine is that any models of care have "an empowered patient in a shared decision-making partnership with the clinician" where impact of treatment or no treatment is weighed up (Scottish Government

2016 p.9). The first report was written while some of the data collection in Phase 2 was being carried out but echoes with the sense that life goes on despite the cancer diagnosis (or any diagnosis) therefore engagement with individuals to find out their preferences is key.

> *"Real people have real lives, real stories, real problems and real priorities and, therefore, no person is a 'typical' member of the public. So, when engaging with the public, one tends to encounter a diversity of views, sometimes with subtle yet important differences. Capturing such views can be more of an art than a science." (The Scottish Government 2019, p.15)*

Where there is potential to remove residual disease in resectable liver metastases, the intent of treatment is not palliative, yet as is evidenced by this study, there is a propensity for scenarios to quickly become palliative. The value of this study is that it has included eight patients in total who due to a number of reasons, were not able to proceed to liver resection as this displays the reality of the pathway. The further reality is that in Phase 1, five patients were no longer alive a year after interviewing and likewise 4 patients in Phase 2. All were cases of recurrence, either in the liver or elsewhere that made surgery not possible. This demonstrates the unpredictability of the nature of disease and how a realistic approach to what is possible requires to be discussed with the patient in their everyday world. To me, this fits in with the thinking behind the Family Illness model as explained in Chapter 7.

The interesting thing is that not one person when weighing up the risks of liver resection or potential recurrence, declined potential treatment. Very much in the same way that Snyder (2000) uses hope theory, the goal of liver resection was something to be attained. It was held up and patients were guilty of planning their way to it in the same way that life goals could be worked up and conquered. Perhaps this was because all of the individuals had little or no clinical symptoms so there was nothing to resonate that they were unwell. Yet, health cannot be conquered in the same way that life goals can. Gadamer spent much discussion on this, in his Enigma of Health, 1996, (Šolcová, 2008) whereby disease was only known by what was absent and that absence was health. Participants in this study had a thirst for life and a desire for survival. Perhaps this was because the CRLM pathway gave them hope by the mere fact that they were on it until they came off it. This is very different to other health situations or scenarios where people have lost hope and have no desire for survival, suicide here being the scenario that comes to mind. Due to the fact that the situation can change quickly the intent of resultant treatment can change to palliative intent. At this stage a further discussion regarding realistic treatment will need to occur. One of the benefits of social media is that it

has helped to challenge living with life limiting illness in a more positive way. Examples of this include Hannah Francis, Doddy Weir and Kate Gross, the journalist who herself was diagnosed with metastatic bowel cancer and later died when her twins were four years old. Preparation for the end of life, whilst still living a full life, became key for Hannah and Kate. This study has unintentionally given affirmation to the role of the nurse specialist and has given insight into some of the complex and often invisible communication work that nurse specialists carry out, balancing hope and preparing for uncertainty.

9.8 Surgically resectable metastases: a new conceptual understanding

Having determined that the overall intention of CRLM does not sit comfortably with palliative care, there are some challenges in how we continue to perceive colorectal liver metastases both as health professionals and in how we communicate to patients. Clark (2002) writes that palliative care opened up a space somewhere between the hope of cure and acceptance of death. Having access to the CRLM represents that active hope of being disease free and as the interviews have shown all 32 patients wanted to take that hope. We need a new way of conceptualising metastatic disease and utilising how we use hope where previously this had not been the case in metastatic disease.

Throughout the interviews, hope was rarely labelled as such by using the word 'hope' or any derivatives of the word 'hope'. However, by digging below the surface of the spoken words used, the sentiment of hope is evident in its expression across different elements of the pathway, all the way through from diagnosis, treatment planning and after a decision was made about liver operability. It is a pathway centered on hope. There is an ebb and flow of hope identified across the pathway and hope is sought at different stages of the pathway for individual reassurance and to foster the ability to move on to what is perceived as the next stage either in treatment or conceptualising survivorship. What is required is a skilled and nuanced form of communication in order to assist with this. What shape this takes is created through understanding the potential difficulties of the CRLM pathway and through listening to the priorities of individuals as they go through treatment.

9.9 Giving shape to hope

Through discussion in Chapter 5 it was apparent that 'hope' is a commonly assumed concept yet a multi-faceted and often elusive concept at the same time. It is used within a continuum of situations from the mundane to the poignant. Hope without effort is often viewed as a

weakness and believed not to be enough on its own, as exemplified often in times of war and political strife and evidenced in Chapter 4. This idea sits more comfortably in situations where we can exert some control over situations, much like Snyder's (2000) goal attainment theory but this falls short in cancer where favourable outcomes have more to do with cell biology rather than mustering up strength to overcome cancer. Similar to the concept of health as discoursed by Gadamer (2013) it is also known by its presence of absence. It can also differ widely in personal experience and does not remain static. It is because of such factors that it is a highly versatile belief and often an asset in personal circumstances. As health professionals we often talk about pathways as having very distinct pivotal points and a range of resultant flow chart systems that stem from major decisions. For patients, they do not know the path that they step out on but they do know that it has a beginning and as understood in this study, they only see the clearer path once they have walked further upon it. At the point of journey entry, hope for liver resection is at one of the peak points because the future cannot be known as the following suggests,

> *"It is only because we do not know what the future holds for us that we can have hope." (Hastie & Dawes 2001, p.328)*

There are four key considerations from the research that are essential in utilising hope in this area. They do not attempt to provide answers but operate as discussion points from which to view current individual practices in this area.

9.9.1 Emerging pathways require an evolution of communication

Only on reflection and glancing back can we see where we have come from and in same way only by looking back at medical progress in this area can we see how far advances have been made in treatment of CRLM. What has been clear from this study in fusing the horizons of both patients and health professionals is that as pathways emerge and develop in response to treatment advances, there is a need for communication about those pathways also to evolve.

Many patients have indicated that they have only understood the pathway from being through it, i.e. that longer vista is required. Equally health professionals are well placed to know the possible twists and turns of the pathway as those with a viewpoint of those with longer vision. Communication skillset is something which has adapted in response to this pathway. Some of the initial set of patients were diagnosed in 2010 at a time when the frequency of CRLM was not what it was now. It may be that at the time health professionals

adopted a more cautious communication style pointing out and reinforcing what might go wrong because it was more unchartered territory. In adopting this more cautious approach, it may be hope was taken away or harder to utilise as a resource. The example of Paul as discussed in Chapter 6 may suggest this. However, as time continues and confidence in the pathway grows, health professionals may reflect a more nuanced and hopeful communication style. The possibility of not getting to the goal of surgery is always there but perhaps may not be laboured at every turn, just as no doubt was the case in any surgery of progress for example, the early heart transplant surgeries may have followed a similar over cautious communication style, although there is no evidence for this. That is not to suggest that risks are not properly addressed and discussed. There is also the challenge for health professionals learning how to communicate in response to certain situations that present themselves as the likelihood of liver resection begins to slip away. This was something recognised clearly from the health professional focus group in Phase 1.

If anything, the stories depicted are of keeping realistic hope alive throughout the process. After all, the interviews have shown that the participants were in no doubt that once spread has occurred into the liver, it is not good news. This clearly starts the terminal time clock ticking. The data supports that individuals do not need constant reminding that this could be the case but that they want to keep hope evident. This links in with the importance of a therapeutic relationship with health professionals as outlined in section 9.8.4.

9.9.2 Hope has a language

There are two aspects of language that need to be considered, the first is the language used by the health professionals and the second relates to that used by patients. Several accounts by the participants in this study have shown that certain language used can have a lasting negative and detrimental emotional effect to patients. The most memorable of this was Ellen's description of the word 'borderline' and 'futile' in Phase 1 being used while she was waiting on the ward for her surgical theatre space to come. In this case the technical use of borderline dispelled hope. We must be cautious that technical language that contains specific medical knowledge may have a different and negative meaning for patients than it does for us as health professionals. Where we do use technical language, we need to allow time to explain it. Ellen's situation had allowed little time for explanation. In the second phase, there were more positive examples of the use of language. This may have also represented some change in health professionals becoming more confident with the pathway. In addition,

having the presence of nurse specialists routinely involved at points throughout the pathway, means that patients have an opportunity to discuss any use of language that has uncertain meaning. This is something which is often evident from working in this area where patients check and clarify words or phrases that have been used during consultation either after the consultation or by ringing following to check.

The other language situation is a pattern often seen expressed by patients and that is the apparent expression of denial after a treatment option has been closed. This does not just occur in this group of patients but it is one that occurred for those who were not able to proceed to liver resection in both phases. There were two strong cases where this occurred. The first was Sam in Phase 1 who, after interviewing him in his home, alongside his wife, I was left wondering had I been unethical in recruiting him to the study. During the interview I became concerned that it had not been communicated to him clearly enough as he still seemed to be talking about getting to the liver surgery or whether it had been clearly communicated but he had been denying it. Such thought around genuine denial vs a misleading denial had been something that earlier in my career I had often contemplated when people pass on information about a patient and their understanding of how grave their health situation was. My experience and to that end, these data would suggest that very few people have a true denial. Often what looks like a denial is oddly enough people expressing a sense of hope. I was relieved to see that this is something which Frank (2014) had also struggled with. In his paper, 'Finding ways to hope, seeing beauty', he uses a personal example of his father seemingly not to grasp the situation that his mother was dying and he talked about a future event as a goal that his wife would not make. Frank had thought that both himself, and the hospice had communicated clearly that his wife was dying, only for Frank to realise that what his father was doing was using the agent of hope while knowing the reality of what would happen. He recounts that his father's reluctance to name the situation was not denial but 'it was an affirmation of life as it remained' (Frank 2014, p.143).

In some ways, this use of hope was a transition between the hopeful state we have when we do not have enough information and acceptance of a new situation. Careful analysis and reflection on Sam's interview, made me realise that he did know that liver resection was not possible but that he was really saying, 'if only it were possible'. This was also experienced in Timothy's interview in Phase 2 when he drew on hope to express that if the chemotherapy (palliative) worked he might still get to liver resection the but by this time, I was comfortable

with the signs that he knew that he would not make it to liver surgery. The challenge for us as health professionals is not to label denial too readily but to consider that the verbalisation of what cannot be, is often bridging the gap between what is no longer possible and considering what that will mean for their immediate future. Careful assessment of everything else patients are expressing in order to consider the whole of the story and not just the part is necessary. We need to avoid potential conflict over patient management if we arrive at different perspectives at different times, just as Frank also had to resist conflict with his father.

9.9.3 Hope is more than that embedded in treatment

Having a treatment plan when liver metastases were diagnosed was identified as critical to participants. It gave participants hope as discussed in Chapter 6 and several participants noted that this is how they were helped to get control back in a situation that seemed beyond their control. In this way a plan fuels hope and it could be said that hope equalled a plan. However, as seen by those participants who did not proceed to liver surgery, hope is more than treatment alone. This is critical for us as health professionals, as we need to be reminded that hope is not only evident in survivorship. There are different ways to hope. When the possibility of liver resection is removed, life suddenly becomes very limited. Several patients spoke about the devastation which that news brought. Transitioning into this phase of understanding that life may be shorter than thought is important. Some patients spoke of the clarity that this time brought to them and that an admiration for the aesthetics and beauty in life is sharpened, very much as Kate Gross described in her autobiographical account of living with metastatic disease (Gross 2015). There is a median survival of 5-20 months (Valderrama-Treviño et al 2017) for patients with liver only metastases who are have systemic anti-cancer therapy, with figures towards the end of this median being more common. This means that a rapid decline is unlikely but helping to prepare patients for the end of life also becomes part of good practice from within the same cancer team. As mentioned before, the impetus for including patients who did not receive liver resection, was to include the reality of the caseload. This means that those patients who do not proceed to liver resection require care that is responsive to their needs alongside those that patients who do proceed to liver resection.

Our desire in the nursing team is that the message of living with cancer is emphasised yet at the same time our experience of working alongside patients highlights some of the desires

that patients have in preparing for what they know will happen. To hold this in balance is what appears to be me as the 'now but not yet' approach that life is limited. This takes into account an acceptance of the situation in the now. This may involve a number of personal planning approaches for the inevitability, but life is for living until this point.

One of key aids to this is the priorities approach as helpfully set out by Atul Gwande (2014). Priorities, I believe, are closely related to accessing hope. After interviewing over 200 people with terminal or chronic illness and including frontline staff involved in their care, Atul Gwande (2014) concluded that he learnt important lessons about people's sense of priorities. Gwande (2014) notes that people have priorities that they want to serve and that the best way to find out priorities is to ask them.

> *"The most reliable way to learn what people's priorities are (and there are highly technical studies on this), is to ask. And we don't ask."*
> *(Gwande 2014, live broadcast, Reith Lecture series, Edinburgh)*

He goes on to say that asking has a special power. If we do not ask, we take away the opportunity for people to voice priorities and we take away the opportunity to give shape to their lives, to pass on wisdom, to allow for meaning. It opens people up and gives them the opportunity to face their anxieties by putting them into their own words. This is not done by listing medical facts. This is obviously done on the understanding that the facts and figures about their condition have been discussed but it is not the whole picture to care for them and leave them at this stage.

Gwande (2014) refers to four guiding questions that seek to elicit a sense of an individual's priorities.

(1) What is your understanding of where you are with your illness at this time?
(2) What are your fears and worries for the future?
(3) What are your goals if time is short?
(4) What outcomes would be unacceptable to you?

Again, it takes skill and sensitivity to ask these questions. This is not just some tick box exercise. It takes time to listen and time to ask but if addressed especially when treatment options come to an end, can give permission for individuals to prepare for the end of life. Perhaps it is no surprise that Gwande's book 'Being Mortal' (2014) and the Realistic Medicine international movement were occurring at the same time (Scottish Government 2016). Both

have been a reminder of the need to temper expectations in the midst of treatment advances where not everything is possible.

9.9.4 Relationship: a mechanism for facilitating hope

To conclude this section, this study has demonstrated the centrality of the health professional relationship in facilitating hope. Although, indeed valued across health care professional teams in surgery and hepatobiliary care, the patient- professional relationship within the oncology setting was intensely instrumental in having a guiding role through the CRLM, and in the facilitation of hope. The nurse specialist, working across all three teams, was identified by patients as having a role that was indispensable to them by way of access, knowledge and a holistic sense of support, understanding their particular context of life. The combined support intervention was seen to enhance the nurse-patient relationship that went far beyond the face to face encounters at clinic consultations or treatment areas. As has been argued, it is the consistency of this relationship over time, that served to maintain an individual's sense of hope which, in itself, remained evident, regardless of the eventual outcome of feasibility of CRLM. An unexpected finding from the study was the therapeutic value that participants found through the process of the relationship based interview. This could further be explored by way of patient invitation to meet with the nurse specialist at a specified interval (for example, 6-12 months) post liver resection as a time to pause, reflect back on treatment but maintain the focus on the future. In addition, there may be value in nurse specialists facilitating follow-up for patients post liver resection, in much the same way as has been modelled for primary follow-up patients (Knowles et al 2007). This would meet the requirements for detection of metastatic disease, the management of treatment side effects and ongoing emotional adjustment to the impact of treatment.

9.10 Limitations of the study

One of the limitations of the study was the length of time taken to gather the data for Phase 2. In Phase 1, invitation to the study was based on those who had already undergone or been considered for liver surgery. In Phase 2, invitations could only be made prospectively and because of the complexity and involvement of multimodal treatment, this could mean an elongated pathway for patients, especially for those diagnosed with a synchronous metastases but not able to have synchronous surgery or for those having down staging treatment for a rectal cancer prior to consideration of liver metastases. While, patients were recruited in a reasonable and predictable timeframe of 6 months for Phase 2 having had liver

resection, it took a further 9 months to complete recruitment for those patients who were eventually considered ineligible. They could not be approached until it had been clear that the decision had been discussed by the medical team that they could not proceed with liver resection. To have done so any earlier, would have not only been unethical but would have been detrimental to an individual's understanding of working through the process when their one sole aim was to proceed to liver surgery. In one sense, the difficulty of not having a larger number to recruit from in those individuals not proceeding to liver resection could be interpreted as better clinical decision making. As much as the clinical team want to keep options open for individuals with disease that appears to be resectable, there is also the need for adequate patient selection with clear intentions of treatment so as not to unduly give false hope about a situation. Equally the smaller pool of such individuals may also represent the nature of disease in these patients at this time as at the time of writing, there were a number of patients in quick succession who were deemed not able to proceed with liver resection. Either way, this displays some of the realistic struggles in negotiating the logistics that present during research, many of which are unpredictable and making decisions in response to such challenges when the study is often bound by time and finances.

A further limitation may be seen in using a different approach for participants and health professionals. Considering the methodological emphasis was on phenomenology throughout the study, in combination of delivering a service change, one might ask why were the health professionals in Phase 1 and Phase 2 not interviewed in a similar way to the participants rather than collectively in a focus group? This has been referred to in Chapter 5 but the reasons being were that the health professionals did not have the same horizon of first-hand experience of the CRLM pathway as of the participants. For this reason it was justifiable to take a different approach to gain the insight from the health professionals viewpoint. There was no requirement to hear solely the individual voice of the health professional in the same way as the patients' voice. The element of service improvement also meant that a different approach was permissible for the health professionals as they were the ones delivering the service while the patients were on the receiving end of the service.

A known challenge with the acquisition of qualitative data is the time-consuming element of dealing with a large amount of data and subsequently what might be elicited. Issues of reliability were overcome by reading the transcripts with audio recordings and with field notes present. The use of MaxQDA also helped to organise the data and make the stages of

analysis potentially retraceable for another researcher to view. In addition, a selection of interviews from both Phases were read and checked by two independent researchers to affirm themes and check for other missing sub-themes or themes.

Finally, an unexpected consequence of the support model was having no uptake for the buddy interaction. This reveals some of the gritty reality of conducting research in general and came as a surprise set against the expectations from Phase 1. Research can often show us that we can expect something to happen but we cannot guarantee an outcome. This unintended direction is hard to explain but if seen through the eyes of Frank (1995) suggests that one almost has to be distant enough from such a situation before you want to go back and connect with others in a similar situation. He writes about how someone who has experienced deep suffering becomes,

> *'the compassionate being who vows to return to earth to share her enlightenment with others." (Frank 1995 p.119)*

This would correspond with those in Phase 1 who expressed a huge sense of gratefulness for the treatment they had but wanted to give something back to the service and willingly offered to meet others as an action driven by gratitude. This actuality, as Frank (2013) has expressed, falls into the chaos period of illness as discussed in section 9.4 and it is likely that being present in the turmoil of uncertainty prevents engagement with others in a similar situation. There is also the concern that one cannot force an unnatural connections. I expect that the reality of successful peer individual or group support is that a connective chemistry needs to exist and not just the commonality of disease. Commonality is not enough. Certainly, in the buddy evening, I observed a good connection. This could explain how the two participants in Phase 2 attended had a good experience and how the one participant who had contact with a previous surgical peer did not. This lack of chemistry was enough to put him off meeting anyone again in a similar situation. One might expect that the uncertainty experienced in the chaos phase accentuates patient vulnerability. Choosing not to meet peers is therefore one way of reducing vulnerability and maintaining control in a health situation where overall there is limited control.

9.11 Recommendations for future research

Where treatments and subsequent pathways are in evolution, there will always be scope for research. The CRLM pathway is clearly one pathway where transition and unpredictability are evident. In many ways this means that ideas for research into or related to this pathway

have been activated by this study rather than brought to a close by the work contained within this thesis. In addition, the model of support developed in the interim period, with systematic telephone review, information series and patient buddy may have value in other areas, such as the colorectal lung metastases pathway. Recommendations for future research proposals, can be seen to be as follows:

• To explore hope directly in this pathway by using Herth's Hope Index (Herth 1992) in use of mixed methods research, combining qualitative research to specifically explore what gives hope in pathways of uncertainty.

• To conduct interviews with family members to look at the wider and often hidden aspects of family experience. This is particularly relevant when considering the context of the family in the Family Illness Model approach to care.

• To conduct a similar study in a different geographical area.

• To conduct a qualitative study exploring the emotional labour (as defined by Hochschild in 1983 (2012) and further developed by Smith, (2010, 2012)) of nurse specialists, plus or minus additional members of the multidisciplinary team involved in the complex management of patients being considered for CRLM.

• To conduct a qualitative study exploring the language of uncertainty and its effect on hope as a framework for understanding the experience of cancer in complex surgery for metastatic cancer.

9.12 Policy/ practical recommendations

A further number of policy related recommendations can be drawn from this study, despite current complexities in operational infrastructures.

• Given the need for liver imaging to be reviewed by liver surgeons, there is a need for novel ways to connect liver teams from specialist centres based in different geographical areas.

• In line with the above point, and the evidential benefit of CRLM, there may be a value in instituting Quality Performance Indicators (QPIs) for different settings and centres. This may help to facilitate appropriate referral to the hepatobiliary team in particular.

• Given the anxiety burden, by such patients waiting for CRLM, it may be worth considering time guidelines to liver resection/metastatic surgery with potential curative intent, reflective of treatment guidelines for colorectal primary surgery.

• Given the complexity of such pathways, there is a growing need to attend specifically to the needs of patients having surgical resection for colorectal metastases. This however, will mean additional input of nursing resources to support this work and may require the separation of the primary and secondary colorectal case load within the future.

• Given the rapidly evolving practice of surgical resectability of metastatic disease, (liver and other sites), there is a need to maintain educational awareness among health professionals caring for patients on complex pathways for surgical resection. This may also include

education on the way metastatic liver disease is framed, the use of supportive language in communicating complexity with patients and an understanding of the emotional burden carried by individuals being considered for surgical resection of metastases. Nurse specialists would be well placed for educational invovlement in this area.

9.13 Chapter summary

This study has explored the experiences of patients being considered for resection of liver metastases from a colorectal primary. Bringing this thesis to a close, presents an opportunity to look back at the overall journey with three clear destination points along the way; the guiding motivation for the study, how the chosen methodology has given shape to the research and how patient experience has been used to drive forward a service improvement for future patients on the CRLM pathway. Gadamerian philosophy has been of value in giving understanding to the different levels of horizon throughout the study as evidenced by patients, health professionals and myself as researcher. The findings have revealed three overarching horizons from which to view the CRLM pathway; patient expectation, uncertainty and personal understanding. The resultant findings have revealed that collectively, the stories presented are less about the pathway itself, but essentially are stories of hope in the context of potentially resectable metastatic disease. This has implications on how as health professionals we give shape to hope throughout that pathway. The study has also been an affirming piece of work for the role of the specialist nurse who has a key role in working alongside patients and utilising their inside knowledge of the pathway in order to manage pathway uncertainty and patients' expectations. To conclude, with reference to the context of potentially resectable colorectal liver metastases, hope can be facilitated within a relationship with health professionals in that pathway, hope has a plan, a language and yet hope is more than treatment alone. Hope never rests. As Ruth reflected,

> *"I was taken one step at a time. Looking back, I never lost hope, I've still got hope. I can't not hope because it's the nature of human beings to hope." (Ruth)*

References

Abbas, S., Lam, V. & Hollands, M., (2011) Ten-year survival after liver resection for colorectal metastases: systematic review and meta-analysis, *International Scholarly Research Network*, *ISRN Oncology*, 2011, 763245: pp.1-11.

Abdalla, E., Adam, R., Bilchik, A. et al., (2006) Improving Resectability of Hepatic Colorectal Metastases: Expert Consensus Statement. *Annals of Surgical Oncology*, 13(10), pp.1271–1280.

Abdalla, E. (2011) Resection of Colorectal Cancer Liver Metastases, *Journal of Gastrointestinal Surgery*, 15(3): pp.416-419.

Academy of Medical Royal Colleges (2018) *Please, write to me. Writing outpatient clinic letters to patients: Guidance*, London: Academy of Medical Royal Colleges.

Adam, R., Karam, V., Delvart, V. et al (2012) Evolutions of indications and results of liver transplantation in Europe. A report from the Liver Transplant Registry (ELTR), *Journal of Hepatology*, 57(3): pp.675-688.

Adam, R. & Kitano, Y., (2019) Multidisciplinary approach of liver metastases from colorectal cancer, *Annals of Gasterentological Surgery*, 3(1): pp.50-56.

Al Chalabi, H., O'Riordan, J.M., Richardson, A., et al (2011) Six-Year Experience of a Nurse-Led Colorectal Cancer Follow-Up Clinic, *Surgery Research and Practice,* pp1-5.

Alqahtani S (2012) Update in Liver Transplantation, *Discovery Medicine*, 14(75): pp.133-141.

Alweiss, L., (2002) Heidegger and `the concept of time', *History of the Human Sciences*, 15(3): pp.117–132.

Andersen, M.H., Dueland, S., Hagness, M. et al (2012) Quality of life following liver transplantation in patients with liver metastases from colorectal carcinoma, *Scandinavian Journal of Caring Sciences*, 26(4): pp.713–719.

Annells, M., (1996) Hermeneutics: philosophical traditions and nursing practice research, *Nursing Science Quarterly*, 8(4): pp.95-102.

Annis, B., (2018) Finding Gratitude and other lessons learned from cancer, in *Cure,* [online] Available at: https://www.curetoday.com/community/bonnie-annis/2018/01/finding-gratitude-and-other-lessons-learned-from-cancer [Accessed 10 Jan.2020]

Aragon, R.J. & Solomon, N.L. (2012) Techniques of hepatic resection, *Journal of Gastrointestinal Oncology*, 3(1): pp.28–40.

Aristotole, (2009) *The Nichomachean Ethics*, Translation by D. Ross, Edited by L. Brown, Oxford: Oxford University Press, pp.3-79.

Atkinson, P. & Silverman, D. (1997) Kundera's Immortality: The Interview Society and the Invention of Self, *Qualitative Inquiry*, 3(3): pp.324-345.

Averill, J.R., & Sundararajan, L., (2005) Hope as Rhetoric: Cultural Narratives of Wishing and Coping, in *Interdisciplinary Perspectives on Hope*, J. Eliott (Ed), New York: Nova Science Publishers, Inc., pp. 133-166.

Avis, H. (2002) 'Whose Voice is that? Making Space for Subjectivities in Interviews', in L. Bondi, (Ed) *Subjectivities, knowledges and feminist geographies: the subjects and ethics of social research*, Oxford: Rowan & Littlefield Publishers Inc., pp.191-207.

Aziz, M.A., Yousef, Z., Saleh, A.M., et al., (2017) Towards personalized medicine of colorectal cancer. *Critical Reviews in Oncology/Hematology*, 118: pp.70–78.

Aziz, N.M. & Rowland, J.H (2003) Trends and advances in cancer survivorship research: challenge and opportunity, *Seminars in Radiation Oncology*, 13(3): pp.248-266.

Bacon, F., (2011) *The works of Francis Bacon*, Spedding, J., Ellis, R. & Heath, D., (Eds, 1859) Cambridge: Cambridge University Press, p.168.

Barab, S., Dodge, T., Thomas, M.K., et al (2007) Our designs and the social agendas they carry, *Journal of the Learning Sciences*, 16(2): pp.263-305.

Bate P. & Robert G., (2006) Experience-based design: from redesigning the system around the patient to co-designing services with the patient, *Quality & Safety in Health Care*, 15(5): pp.307-10.

Baxter S., Muir D., Brereton L., et al (2016) Evaluating public involvement in research design and grant development: Using a qualitative document analysis method to analyse an award scheme for researchers, *Research Involvement and Engagement,* 2(13): pp.1-15.

Beals, F., Kidman, J. & Funaki, H., (2019) Insider and Outsider Research: Negotiating Self at the Edge of the Emic/Etic Divide, *Qualitative Inquiry*, 26(6): pp.593-601.

Beaver, K., Latif, S., Williamson, S., et al (2010) An exploratory study of the follow-up care needs of patients treated for colorectal cancer, *Journal of Clinical Nursing*, 19(3): pp.291-300.

Beckman, E.S., Helft, P.R. & Torke, A.M., (2013) The Content of Hope in Ambulatory Patients with Colon Cancer, *Narrative Inquiry in Bioethics*, 3(2): pp.153–164.

Beyleveld, D. & Ziche, P., (2015) Towards a Kantian Phenomenology of Hope, *Ethical Theory and Moral Practice,* 18(5): pp.927–942.

Bijlani, R.L. & Manjanatha, S., (2011) Circulation in Bijlani RL & Manjanatha S, *Understanding Medical Physiology: A Textbook for Medical Students*, 4th Edition, New Delhi: Jaypee Brothers Medical Publishers, pp. 199-203.

Binefa, G., Rodríguez-Moranta, F., Teule, A., et al., (2014) Colorectal cancer: from prevention to personalized medicine, *World Journal of Gastroenterology*, 20(22): pp.6786–6808.

Bjørk, I.T. & Nåden. D., (2008) Patients experience of waiting for a liver transplantation, *Nurse Inquiry*, 15(4): pp.289-298.

Bloeser, C. & Stahl T. (2017) 'Hope' in *The Stanford Encyclopedia of Philosophy,* E.N. Zalta (Ed), (online) Available at: https://plato.stanford.edu/cgi-in/encyclopedia/archinfo.cgi?entry=hope [Accessed 15 May 2019]

Bobier, C.A., (2017) Hope and practical deliberation, *Analysis*, Practical Deliberation, 77(3): 495-497.

Boeck, P.R. (2014) Presence: A concept analysis, *SAGE Open*, 4(1): pp.1-6

Bondi, L., (2013) Understanding feelings: Engaging with unconscious communication and embodied knowledge, *Emotion, Space and Society*, pp. 1-11.

Boote J.D., Twiddy M., Baird M., et al., (2013) (Supporting public involvement in research design and grant development: a case study of a public involvement award scheme managed by a National Institute for Health Research (NIHR) Research Design Service (RDS), *Health Expectations*, 18(5): pp.1481-1493.

Bowel Cancer Australia (2018) *Liver metastases,* (online) Available at: https://www.bowelcanceraustralia.org/treatment-metastatic-bowel-cancer#LiverMetastases [Accessed 8 Aug. 2018]

Brandi G., De Lorenzo, S., Nannini, M., et al (2016) Adjuvant chemotherapy for resected colorectal cancer metastases: Literature review and meta-analysis, *World Journal of Gastroenterology*, 22(2): pp.519–533.

Briggs, B., (2016) 'Researching your own cancer online? Dive in or stay clear?' in *Fred Hutch Research*, [online] Available at: https://www.fredhutch.org/en/news/center-news/2016/02/researching-your-cancer-online.html [Accessed 15 Jan 2020]

Brown, J., Sorrell, J.H., McClaren, J. & Creswell, J.W. (2006) *Qualitative Health Research*, 16(1): pp.119-136.

Brown, L.F., Kroenke, K., Theobald, D.E., et al (2010) The association of depression and anxiety with health-related quality of life in cancer patients with depression and/or pain, *Psychooncology*, 19(7): pp.734–741.

Brudvik, K.W., Passot, G. & Vauthey, J.N., (2016) Colorectal Liver Metastases: A Changing Treatment Landscape, *Journal of Oncology Practice*, 12(1): pp.40–41.

Bryman, A., (2016a) 'Social research strategies: quantitative research and qualitative research', in A Bryman (Ed), *Social Research Methods*, Oxford: Oxford University Press, pp.16-38.

Bryman, A. (2016b) 'The nature of qualitative research', in A Bryman (Ed), *Social Research Methods*, Oxford: Oxford University Press, pp.374-406.

Bryman, A. (2016c) 'Interviewing in Qualitative Research', in A. Bryman (Ed), *Social Research Methods*, Oxford: Oxford University Press, pp.465-499.

Bryman, A. (2016d) 'Computer assisted qualitative data analysis: using NVivo, in A. Bryman (Ed), *Social Research Methods*, Oxford: Oxford University Press, pp.601-617.

Buckley A., Corless, L., Mee, S. et al (2016) Patient narratives 1: using patient stories to reflect on care, *Nursing Times*, 112(10): pp.22-25.

Buell, J.F., Cherqui, D., Geller, D.A., et al (2009) The international position on laparoscopic liver surgery: The Louisville Statement, 2008, *Annals of Surgery,* 250(5), pp.825–830.

Butler-Bowden, T. (2013) 'Philosophy Classics: Fragments, 6th Century Heraclitis, in *50 Classic Series*, [online] Available at: http://www.butler-bowdon.com/heraclitus---fragments.html [Accessed: 15 Jan. 2020]

Campbell, A., (2015) Introducing a buddying scheme for first year pre-registration students, *British Journal of Nursing,* 24:(20): 992-996.

Cancer Research UK (2017) *Cancer Risk Statistics*, [online], Available at: https://www.cancerresearchuk.org/health-professional/cancer-statistics/risk [Accessed 5 Nov. 2017]

Cancer Research UK (2019a) *Bowel Cancer Survival Statistics*, [online], Available at: https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/bowel-cancer/survival#heading-Three [Accessed 5 Dec. 2019]

Cancer Research UK (2019b) *Bowel Cancer Survival Statistics*, [online], Available at: https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/bowel-cancer/survival#heading-Zero [Accessed 5 Dec. 2019]

Cao, W., Qi, X., Yao, T. et al., (2017) How doctors communicate the initial diagnosis of cancer matters: cancer disclosure and its relationship with Patients' hope and trust, *Psycho-Oncology*, 26(5): pp.640–648.

Capps, D., (2016) Imagining Hope: William F. Lynch's Psychology of Hope, *Pastoral Psychology*, 65(2): pp.143–165.

Capussotti, L., (2011) in *Surgical treatment of colorectal liver metastases*, L. Capussotti (Ed) New York: Springer, preface, pp. xi-x, 1-34.

Cassidy, E., Reynolds, F., Naylor, S. et al., (2011) Using interpretative phenomenological analysis to inform physiotherapy practice: An introduction with reference to the lived experience of cerebellar ataxia, *Physiotherapy Theory and Practice,* 27(4): pp.263–277.

Cercek, A., Braghiroli, M.I., Chou, J.F., et al (2017). Clinical Features and Outcomes of Patients with Colorectal Cancers Harboring NRAS Mutations. *Clinical Cancer Research : an official journal of the American Association for Cancer Research*, 23(16): pp.4753–4760.

Clark, D. (2002) Between hope and acceptance: the medicalisation of dying, *British Medical Journal*, 324: pp.905-7.

Clark, J., (2008) Philosophy, understanding and the consultation: a fusion of horizons. *The British Journal of General Practice*: 58(546): pp.58–60.

Charalambous, A., Wells, M., Campbell, P., et al., (2018) A scoping review of trials of interventions led or delivered by cancer nurses, *International Journal of Nursing Studies*, 86: pp.36–43.

Chiappa, A., Makuuchi, M., Lygidakis, N.J. et al (2009) The management of colorectal liver metastases: Expanding the role of hepatic resection in the age of multimodal therapy, *Critical Reviews in Oncology Hematology*, 72(2009): 65-75.

Choong K.C. & Ammori J.B., (2014) Surgical management of colorectal liver metastases, *Open Access (OA) Cancer*, 2(1):6.

Chow F.C.L. & Chok K.S.H., (2019) Colorectal liver metastases: An update on multidisciplinary approach, *World Journal of Hepatol*ogy, 11(2): pp.150-172.

Chowdhury, M.M., (2010) Techniques for Liver Resection, *Bangabandhu Sheikh Mujib Medical University Journal* (*BSMMU)*, 3(2): pp.112-119.

Christiansen, S., Oettingen, G., Dahme, B. & Klinger, R., (2010), A short goal-pursuit intervention to improve physical capacity: A randomized clinical trial in chronic back pain patients, *Pain*, 149(3): pp.444-452.

Chu, H.K., Sondenaa, K., Tsiotos, G.G., et al (2004) Concurrent vs. staged colectomy and hepactectomy for primary colorectal cancer with synchronous hepatic metastases, *Diseases of the Colon and Rectum*, 47: pp.1310-1316.

Cibangu, S.K., (2010) Paradigms, methodologies, and methods, *Library & Information Science Research*, 32(3): pp.177-178.

Collins, D., & Heidi, Chua., (2017) Contemporary surgical management of synchronous colorectal liver metastases, *F1000Research*, 6,598: pp.1-7.

Colquhoun, M. & Hill, V., (2011) Sustaining hope in people with cancer: developments in palliative and end-of-life care, in *Perspectives on Cancer Care*, J.N. Fawcett & A. McQueen (Eds), Chichester: Wiley-Blackwell, pp. 229-249.

Corbin, J. & Morse, J. (2003) The Unstructured Interactive Interview: Issues of Reciprocity and Risks When Dealing With Sensitive Topics, *Qualitative Inquiry*, 9(3): pp.335-354.

Conrad, P., (2005) The shifting engines of medicalization, *Journal of Health Social Behaviour*, 46; pp.3-14.

Cook, O., MacIntrye, M., Recoche, K., et al., (2019) "Our nurse is the glue for our team" - Multidisciplinary team members' experiences and perceptions of the gynaecological oncology specialist nurse role, *European Journal of Oncology Nursing,* 41: pp.7–15.

Cooper, A.B. & Curley, S.A. (2013) Surgical treatment of colorectal liver metastases, *Chinese Clinical Oncology*, 2(2): pp.1-9.

Cram F (2013) 'Method or methodology, what's the difference?', in *Whānau Ora*, [online] Available at: http://whanauoraresearch.co.nz/news/method-or-methodology-whats-the-difference/ [Accessed 10 June 2018]

Critical Appraisal Skills Programme, (2018) CASP (Qualitative Checklist), [online] Available at: https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf) [Accessed: 3 May 2019]

Cutcliffe, J.R. & Kaye, H., (2002) The concept of hope in nursing 1: its origins, background and nature. *British Journal of Nursing*, 11(12): pp.832–840.

de Liguori Carino, N. et al., van Leeuwen, B., Ghaneh, P., et al (2008) Liver resection for colorectal liver metastases in older patients, *Critical Reviews in Oncology and Hematology*, 67(3): pp.273–278.

Denlinger, C.S. & Barsevick, A,M. (2009) The challenges of colorectal cancer survivorship, *Journal of the National Colorectal Cancer Network*, JNCCN, 7(8): 883-893.

Department of Health (DH) (2000) *The NHS Plan: A Plan for Investment, a Plan for Reform,* London: DH.

Department of Health, (DH) (2004) *NHS Improvement Plan: Putting People at the Heart of Public Services*, London: DH.

Department of Health, (DH) (2005) *Creating a patient-led NHS: Delivering the NHS Improvement Plan'*, London: DH.

Department of Health, (DH) (2007) *Our NHS, Our Future*, London: DH.

Department of Health, (DH) (2011) *Improving outcomes: A Strategy for Cancer*, DH; London.

Department of Health, (DH) (2014b) *The Mandate: A Mandate from the Government to the NHS England April 2014 to March 2015*, London: DH.

Department of Health, (DH) (2014b) *The NHS Outcomes Framework 2015/2016: What we heard and the Government's Response*, London: DH.

Diamond, J., (1999) C: Because Cowards get Cancer Too, London: Vermillion.

di Cesare, D., (2013) Gadamer: a philosophical portrait, (Translation by N. Keane), Indiana: Indiana University Press.

di Benedetto, F., Berratta, M., D'Amico, G., et al., (2011) Liver resection for colorectal metastases in older adults: a paired matched analysis, *Journal of the American Geriatrics Society*, 59(12): pp.2282–2290.

Dickinson, E., (2016), *The Collected Poems of Emily Dickinson*, Boston: Digireads.

Dickson-Swift, V., James, E.L., Kippen, S. et al., (2007) Doing sensitive research: what challenges do qualitative researchers face?, *Qualitative Research*, 7(3): pp.327-353.

Diener, E. & Crandall, R., (1978) *Ethics in Social and Behavioural Research*, Chicago: University of Chicago Press.

Diener, E., (1984) Subjective well being, *Psychological Bulletin*, 95: pp. 542-575.

Dizon, D.S (2012) The power of words in cancer care, in *Kevin MD* [online] Available at: https://www.kevinmd.com/blog/2012/05/power-words-cancer-care.html [Accessed 18 Jan 2020]

Dhir, M. & Sasson, A.R., (2016) Surgical Management of Liver Metastases From Colorectal Cancer, *Journal of Oncology Practice*, 12(1): pp.33–39.

Dobrosavljev, D., (2002) Gadamer's Hermeneutics as practical philosophy, *Philosophy, Sociology and Psychology* 2(9): pp.605-618.

Dockett, S. & Perry, B., (2005) "A buddy doesn't let kids get hurt in the playground": Starting school with buddies, *International Journal of Transitions in Childhood*, 1: pp.2-34.

Donati, M., Stavrou, G.A. & Oldhafer, K.J., (2013) Current position of ALPPS in the surgical landscape of CRLM treatment proposals, *World Journal of Gastroenterology*, 19(39): pp.6548-6554.

Dowling, M., (2007) From Husserl to van Manen. A review of different phenomenological approaches, *International Journal of Nursing Studies*, 44(1): pp.131–142.

Doyle, N., (2008) Cancer survivorship: evolutionary concept analysis, *Journal of Advanced Nursing*, 62(4): pp.499–509.

Dufault, K. & Martocchio B.C., (1985) Symposium on compassionate care and the dying experience. Hope: it's spheres and dimensions, *The Nursing Clinics of North America*, 20(2): pp.379-391.

Duška, F., (2017) 'Gadamer's Hermeneutics as Practical Philosophy', in *Hermeneutic Philosophies of Social Science* , B. Babich (Ed) Berlin: De Gruyter, pp.219-236.

Earle, V., (2010) Phenomenology as research method or substantive metaphysics? An overview of phenomenology's uses in nursing, Nursing Philosophy, 11(4): pp.286–296.

Eaton, L., (2002) Patients should be sent copies of doctors' letters about them. *British Medical Journal*, 325(7372): p.1056.

Ekberg, H., Tranberg, K.G., Andersson, R., et al (1986) Determinants of survival in liver resection for colorectal secondaries. *British Journal of Surgery*, 73(9): pp.727-731.

European Organisation for Research and Treatment of Cancer (EORTC) (2019) QLQ-C30, QLQ-C38, *EORTC* [online] Available at: https://www.eortc.org/ [Accessed 30 Oct. 2019]

Fallowfield, L. & Jenkins, V., (2004) Communicating sad, bad, and difficult news in medicine, *The Lancet*, 363(9405): pp.312–319.

Farber, N.J., Urban, S.Y., Collier, V.U., et al., (2002) The Good News About Giving Bad News to Patients, *Journal of General Internal Medicine*, 17(12): pp.914–922.

Fawcett, J.N. (2011) 'Cancer: a journey of discovery', in J.N. Fawcett & A. McQueen (Eds) *Perspectives on Cancer Care*, Chichester: Wiley-Blackwell, pp.8-23.

Fielding, N.G. & Lee, R.M., (2002) New patterns in the adoption and use of qualitative software, *Field Methods*, *14*(2): pp.197-216.

Fong, Y., Fortner, J., Sun, R.L., et al (1999) Clinical score for predicting recurrence after hepatic resection for metastatic colorectal cancer: analysis of 1001 consecutive cases, *Annals of Surgery*, 230(3): pp.309-318.

Fontana, A. & Frey, J.H., (2005) The Interview, From Neutral Stance to Political Involvement in Norman K et al (eds) *The SAGE handbook of qualitative research, 3rd Edition*, London: Sage Publications Inc, pp.695-727.

Forte, J., (2016) Explaining Hope in Plato's Philebus, *International Philosophical Quarterly*, 29 June, [online] Available at: https://www.pdcnet.org/ipq/content/ipq_2016_0999_6_28_68 [Accessed 3 Mar. 2018]

Frank, A. (2013) *The Wounded Storyteller: Body Illness and Ethics*, 2nd Edition, London: The University of Chicago Press.

Frank, A.W., (2014) Finding Ways to Hope, Seeing Beauty, *Journal of Pain and Symptom Management*, 48(1): pp.143–148.

Franklin, B., (1848) *The Way to Wealth*, New York: Leavitt, Trow & Co., p.2.

Franzosi, R., Doyle, S, McClelland L. et al., (2013) Quantitative narrative analysis software options compared: PC-ACE and CAQDAS (ATLAS.ti, MAXqda, and NVivo), Quality & Quantity, 47(6): pp.3219–3247.

Fremstedal, R., (2012) Kierkegaard on the Metaphysics of Hope, *Heythrop Journal*, 53(1): pp.51–60.

Gadamer, H.G., (1964) 'Aesthetics and Hermeneutics' in *Philosophical Hermeneutics* (2008), 30th Anniversary Edition, Translation by D.E. Linge, London: University of California Press, pp. 95-104.

Gadamer, H.G., (1966) Man and Language in *Philosophical Hermeneutics*, Second Edition, D.E Linge, (Ed) (2008), London; University of California Press, p.65.

Gadamer, H.G., (2013) *Truth and Method*, Translation revised by J. Weinsheimer, & D.G. Marshall, London: Bloomsbury.

Gadd, D. (2004) Making sense of Interviewee-Interviewer dynamics in narratives about violence in intimate relationships, *International Journal of Social Research Methodology*, 7(5): pp.383-401.

Galloway, S.C. & Graydon, J.E., (1996) Uncertainty, symptom distress and information needs after surgery for cancer of the colon, *Cancer Nursing*, 19: pp.112-117.

García-Alfonso, P. Ferrer, A. Gil, S. et al., (2015) Neoadjuvant and conversion treatment of patients with colorectal liver metastasis: the potential role of bevacizumab and other antiangiogenic agents, *Targeted Oncology*, 10(4), pp.453–465.

Garden, O.J., Rees, M., Poston, G.J., et al (2006) Guidelines for resection of colorectal cancer liver metastases, *Gut*, 55 (Suppl III): iii1-iii8.

Gawande, A., (2007) 'Introduction' and 'Fallibility' in *Complications: A Surgeon's Notes on an Imperfect Science*, London: Profile Books Ltd, pp.3-106.

Gawande, A., (2014a) 'Introduction' in *Being Mortal*, London: Profile Books Ltd, pp. 1-10.

Gawande, A., (2014b) 'The Problem of Hubris, *BBC, The Reith Lectures,* 13 Dec 2014, [online] Available at: https://www.bbc.co.uk/programmes/b04tjdlj [Accessed Jan. 2015]

Gibbs, G.R., Friese, S. & Mangabeira, W., (2002) The Use of New Technology in Qualitative Research, Introduction to Issue 3(2) of FQS, *Forum: Qualitative Social Research*, 3(2): Article 8. [online] Available at: http://www.qualitative-research.net/index.php/fqs/article/view/847/1840 [Accessed 28 June 2018]

Giorgi, A., (1985) *Phenomenology and Psychological Research,* Pittsburgh: Duquesne University Press.

Giorgi, A., (2007) Concerning the Phenomenological Methods of Husserl and Heidegger and their Application in Pyschology, *Collection du Cirp* (1): pp.63-78.

Greenaway, J., (2018) Communitas: belonging and the order of being, *International Journal of Philosophy and Theology*, 79(1-2): pp.194–212.

Greden, J.F., Valenstein, M., Spinner, J., et al (2010) *Buddy-to-Buddy, a citizen soldier peer support program to counteract stigma, PTSD, depression, and suicide, Annals of the New York Academy of Sciences*, 1208(1): pp. 90-97.

Goble, E., W. Austin, D. Larsen et al (2012) Habits of Mind and the Split-Mind Effect: When Computer-Assisted Qualitative Data Analysis Software is Used in Phenomenological Research, *Forum: Qualitative Social Research*, 13(2): Article 2, [online] Available at: file:///C:/Users/sherw/Downloads/1709-7066-1-PB.pdf [Accessed 30 June 2018]

Goldberg, R.M., Montagut Viladot, C., Wainberg, Z.A., et al., (2018) Optimising the use of cetuximab in the continuum of care for patients with metastatic colorectal cancer, *European Society for Medical Oncology, ESMO Open*, 3(4), pp.1-10.

Goodrum, S. & Keys, J.L., (2007) Reflections on Two Studies of Emotionally Sensitive Topics: Bereavement from Murder and Abortion, *International Journal of Social Research Methodology*, 10(4): pp.249-258.

Gorski, D., (2018) 'The deadly false hope of German alternative cancer clinics', in *Science-Based Medicine,* [0nine] Available at: https://sciencebasedmedicine.org/the-deadly-false-hope-of-german-cancer-clinics/ [Accessed 8 Jan. 2020]

Grondin, J., (2004) 'Gadamer's hope', *Renascence: Essays on Values in Literature*, Gale Literature Resource Center, 56(4): 287+ [online] Available at: https://link-gale-com.ezproxy.is.ed.ac.uk/apps/doc/A120045002/LitRC?u=ed_itw&sid=LitRC&xid=f3dbd384 [Accessed 10 April 2019]

Gross, K., (2014) *Late Fragments: Everything I want to Tell You about this Magnificent* Life, London: William Collins.

Gurusamy, K.S., Pamecha, V., Sharma, D., et al (2009) Techniques for liver parenchymal transection in liver resection, Cochrane HepatoBiliary Group, Cochrane Database of Systematic Reviews, (1), [online] Available at: https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD006880.pub2/full [Accessed 14 Oct 2019)

Haarse, J.E., Britt, T., Coward, N.K., et al., (2002) The human hope, *Journal of Nursing Scholarship*, 24: pp.141-147.

Hacking, B., Wallace, L., Scott, S., et al., (2013) Testing the feasibility, acceptability and effectiveness of a 'decision navigation' intervention for early stage prostate cancer patients in Scotland – a randomised controlled trial, *Psycho-Oncology*, 22(5): pp.1017–1024.

Haddad, A., Bani Hani, M., Pawlik, T.M., et al., (2011) Colorectal Liver Metastases, *International Journal of Surgical Oncology*, 2011: pp.1-12.

Hastie, R., & Dawes, R. M., (2001) 'In Praise of Uncertainty' in *Rational choice in an uncertain world: The psychology of judgment and decision making.* London: Sage Publications, Inc., pp.313-334.

Hammer, K., Mogensen, O. & Hall, E.O.C., (2009) The meaning of hope in nursing research: a meta-synthesis, *Scandinavian Journal of Caring Sciences*, 23(3): pp.549–557.

Hansen, B. S., Rortveit, K., Leiknes, I., et al., (2012) Patient experiences of uncertainty - a synthesis to guide nursing practice and research, *Journal of Nursing Management,* 20(2): pp.266–277.

Hauser, D.J. & Schwarz, N., (2019) The War on Prevention II: Battle Metaphors Undermine Cancer Treatment and Prevention and Do Not Increase Vigilance, *Health Communication,* [online] Available at: https://www.tandfonline.com/doi/full/10.1080/10410236.2019.1663465 [Accessed 15 Jan. 2020]

Heidegger, M. (2010) Temporality and Within-Timeness as the Origin of the Concept of Time, in *Being and Time*, Translation by J. Stamburgh, Revised by D.J. Schmidt, New York: State University of New York Press, pp.385-416.

Hebrews, (2018) Chapter 11, Verse 1, The Bible, *New International Version* (UK), [online] Available at: https://www.biblegateway.com/passage/?search=Hebrews+11&version=NIVUK [Accessed 5 May 2018]

Hersey, J., (2019) 'John Locke: The Father of Liberalism' in *The Objective Standard,* [online] Available at: https://www.theobjectivestandard.com/2019/08/john-locke-the-father-of-liberalism/ [Accessed 25 Mar. 2019]

Herth, K., (1990) Fostering hope in terminally ill people, *Journal of Advanced Nursing*, 15(11): pp. 1250-1259,

Herth, K., (1992) Abbreviated instrument to measure hope: development and psychometric evaluation, *Journal of Advanced Nursing*, 17(10): pp.1251-1259

Herth, K., (2000) Enhancing hope in people with a first recurrence of cancer, *Journal of Advanced Nursing*, 32(6): pp.1431–1441.

Herth, K., (2018) 'Humour, hope and health: one nurses's research journey,' in *Reflections in nursing leadership,* (online) Available at: https://www.reflectionsonnursingleadership.org/features/more-features/humor-hope-and-health-one-nurse-s-research-journey [Accessed 5 April 2019]

Henry, R., (2015) The role of the cancer specialist nurse, *Nursing in Practice*, 24 Nov. (online) https://www.nursinginpractice.com/article/ role-cancer-specialist-nurse [Accessed 12 Sept 2019]

Henshaw, S. (2018) Mobile phone user statistics in the UK: how many smartphone users are there? in *Tiger Mobiles.com* [online] Available at: https://www.tigermobiles.com/blog/mobile-phone-usage-statistics/ [Accessed 10 Nov 2019]

Holloway, I. & Wheeler, S., (2002) *Qualitative Research in Nursing*, 2nd Edition, Oxford: Blackwell Science.

Holstein, J. & Gubrium, J. (2004) The active interview in Silverman D, (ed) *Qualitative Research: theory, method and practice*, London: Sage, 140-161.

Home Health UK, (2018) *Colon/Bowel Cancer*, (online), Available at: https://homehealth-uk.com/coloncancer/ [Available 15 Sept. 2018]

Honney, R, Rees, S., Raza, T., et al., (2012) Developing a 'buddy scheme' for foundation doctors, *Clinical Teacher*, 9(4): pp.205–209.

Hochschild, A.R., (2012) The managed heart commercialization of human feeling, (2012 Edition) Berkeley: University of California Press.

Hospital and Anxiety Depression Scale (HADS) (2016) [online] Available at: https://www.svri.org/sites/default/files/attachments/2016-01-13/HADS.pdf [Accessed 5 Sep. 2018]

Hoti, E. & Adam, R., (2008) Liver transplantation for primary and metastatic liver cancers, *Transplant International*, 21(12): pp.1107–1117.

Houssais, S., Oettingen, G. & Mayer, D., (2012) Using mental contrasting with implementation intentions to self-regulate insecurity-based behaviors in relationships, *Motivation and Emotion*, 37(2): pp.224-233.

Hsu, T., Ennis. M., Hood. N., et al (2013) Quality of life in long-term breast cancer survivors, *Journal of Clinical Oncology*, 31: pp.3540-3548.

Hubbard, G., Backett-Milburn. K. & Kemmer, D., (2001) Working with emotion: issues for the researcher in fieldwork and teamwork, *International Journal of Social Research Methodology*, 4(2): pp.119-137.

Issa, K., (2019) 'O snail', cited in Haiku Moment: the snail by Issa, Available at: https://thesublimeblog.org/2019/05/04/haiku-moment-the-snail-by-issa/ [Accessed on 20 Jan. 2020]

Ismaili, N. (2011) Treatment of colorectal liver metastases, *World Journal of Surgical Oncology*, 9(154): pp.1-12.

Integrated Research Application System, (IRAS) [online] Available at: https://www.myresearchproject.org.uk [Accessed 1 Dec 2012]

ISD, (Information, Statistics, Division) Scotland, (2019) Cancer Waiting Times, ISD [online] Available at: https://www.isdscotland.org/Health-Topics/Waiting-Times/Cancer/ [Accessed 2 Feb. 2020]

Iveson, T.J., Kerr, R.S., Saunders, M.P., et al., (2018) 3 versus 6 months of adjuvant oxaliplatin-fluoropyrimidine combination therapy for colorectal cancer (SCOT): an international, randomised, phase 3, non-inferiority trial, *The Lancet Oncology*, 19(4): pp.562–578.

Jones, L.B. & Egan, M., (2000) The transplant experience of liver recipients: Ethical issues and practice implications, *Social Work Health Care*, 31(2): pp.65-88.

Jones, R.P., Jackson, R., Dunne, D.F., et al (2012) Systematic review and meta-analysis of follow-up after hepatectomy for colorectal liver metastases. *British Journal of Surgery*, 99(4): pp.477–486.

Jorgenson, M.L., Young, J.M., Solomon, M.J., (2015) Optimal delivery of colorectal cancer follow-up care: improving patient outcomes, *Patient Related Outcomes Measures*, 18(6): 127-138.

Kafle, N.P., (2013) Hermeneutic phenomenological research method simplified, *Bodhi: An Interdisciplinary Journal*, 5(1): pp.181-200.

Kakai, H., (2002) A Double Standard in Bioethical Reasoning for Disclosure of Advanced Cancer Diagnoses in Japan, *Health Communication*, 14(3): pp.361–376.

Kalanithi P (2006) *When Breath Becomes Air,* London: Penguin, pp.17-226.

Kappes, H., Stephens, E. & Oettingen, G. (2011) Implicit theories moderate the relation of positive future fantasies to academic outcomes, *Journal of Research in Personality*, 45(3): pp.269-278.

Kassahun, W.T., (2015) Unresolved issues and controversies surrounding the management of colorectal cancer liver metastasis, *World Journal of Surgical Oncology,* 13(6): p.1-10.

Kaufman S.B., (2011) The Will and Ways of Hope, in Psychology Today, [online] Available at: https://www.psychologytoday.com/us/blog/beautiful-minds/201112/the-will-and-ways-hope [Accessed 10 July 2019]

Kelle, U. & Laurie, H. (1995) 'Computer Use in Qualitative Research and Issues of Validity' in U. Kelle (Ed) Computer-aided qualitative data analysis: theory, methods and practice, London: SAGE, pp.19-28.

Kempshall, M.S. (2003) The Pilgrim City: Social and Political Ideas in the Writings of St Augustine of Hippo, *The English Historical Review*, 118(479): pp.1347–1348.

Kessels, R.P., (2003) Patients' memory for medical information, *Journal of Royal Society of Medicine,* 96(5): pp.219–222.

Kidd, L. (2011) Psychosocial and information needs of people affected by colorectal cancer are poorly met during follow-up, *Evidence Based Nursing*, 14(3): pp.65-66.

Kierkegaard, S., (1990) *Eighteen Upbuilding Discourses* (Eds) H.V Kong & E.H. Hong), Princeton: Princeton University Press, pp. 205-226.

Kimball, S. & Garrison, J., (1996) Hermeneutic listening: An approach to understanding in multicultural conversations, *Studies in Philosophy and Education*, 15(1), pp.51–59.

King,N. & Horrocks, C., (2010) *Interviews in Qualitative Research*, London: Sage.

Khatri, S., Whiteley, I., Gullick, J., et al (2012) Marking time: The temporal experience of gastrointestinal cancer, *Contemporary Nurse*, 41(2): pp.146–159.

Kleinman, S & Copp, M.A. (1993) *Emotions and Fieldwork*, London: SAGE Publications, Inc.

Knowles, G., Tierney, A., Jodrell, D., et al (1999) The perceived information needs of patients receiving adjuvant chemotherapy for surgically resected colorectal cancer, *European Journal of Oncology Nursing*, 3: pp.208-220.

Knowles, G., Sherwood, L., Dunlop, M.G. et al., (2007) Developing and piloting a nurse-led model of follow-up in the multidisciplinary management of colorectal cancer, *European Journal of Oncology Nursing,* 11(3): pp.212–223.

Knowles, G., Haigh, R., McLean, C., et al (2013) Long term effect of surgery and radiotherapy for colorectal cancer on defecatory function and quality of life, *European Journal of Oncology Nursing*, 17(5): pp.570–577.

Kolev, N., Valentin, I., Anton, T., et al (2014) Surgical Strategies for Liver Metastases from Colorectal Cancer, in Surgery, Diagnostics and Treatment, JSKhan, (Ed) *IntechOpen*, [online] Available from: https://www.intechopen.com/books/colorectal-cancer-surgery-diagnostics-and-treatment/surgical-strategies-for-liver-metastases-from-colorectal-cancer [Accessed 30 Oct.2018]

Kubler-Ross, E., (2014) *On Death and Dying*, New York: Scribner, pp.133-150.

Kuhn, T.S, (2012) *The Structure of Scientific Revolutions,* 50th Anniversary Edition, With an Introductory essay by Ian Hacking, 4th Edition, I. Hacking, (Ed), London: Chicago Press.

Kunin, M. (2009) 'Gingrich and Limbaugh: Poor Priviledged White Men Grappling with Sotomayor', *HuffPost*, Feb. 2009, updated May 2011 [online] Available at: https://www.huffpost.com/entry/gingrich-and-limbaugh-poo_b_209933 [Accessed 5 Jan 2019]

Kvale, S., (2006) Dominance through Interviews and Dialogues, *Qualitative Enquiry*, 12(3): pp.480-500.

Kvale, S., & Brinkmann, S. (2009) Interviews; Learning the Craft of Qualitative Research Interviewing, 2nd Edition, London: Sage.

Lamb, M., (2016) Aquinas and the Virtues of Hope: Theological and Democratic, *Journal of Religious Ethics*, 44(2): pp.300–332.

Lapan, S.D., Quartaroli, M.T. & Riemer, F.J., (2012) 'Introduction to Qualitative Research' in S.D Lapan et al (Eds) *Qualitative research an introduction to methods and designs*, San Francisco: Jossey-Bass, pp.3-18.

Laverty, S., (2003) Hermenutic Phenomenology and Phenomenology: A Comparison of Historical and Methodological Considerations, *International Journal of Qualitative Methods* 2(3)[online] Available at: http://www.ualberta.ca/~iiqm/backissues/2_3final/pdf/laverty.pdf [Accessed 20 June 2018]

Lawn, C., (2006) 'Who is Gadamer? in *Gadamer: A guide for the perplexed*, London: Continuum International Publishing Group, pp. 17-29.

Leary, A. Bell, N., Darlinson, L., et al (2008) An analysis of lung cancer clinical nurse specialist workload and value, *Cancer Nursing Practice*, 7(10): pp.29–34.

Leary, A. & Oliver, S., (2010) *Clinical Nurse Specialist: Adding Value to Care: An Executive Summary*, London: RCN Publications.

Lesurtel, M., Selzner, M., Petrowsky, H. et al (2005) How should transection of the liver be performed? A prospective randomized study in 100 consecutive patients: comparing four different transection strategies, *Annals of Surgery*, 242: pp.814-823.

Levinson, J.L. & Olbrisch, M.E. (1987) Shortage of donor organs and long waits, Psychosomatics: *Journal of Consultation Liaison Psychiatry*, 28(8): pp.399-403.

Leung, L., (2015) Validity, reliability, and generalizability in qualitative research, *Journal of family medicine and primary care,* 4(3): pp.324–327.

Lilly (2019), Erbitux, (online) Available at: https://www.erbitux.com/mcrc/what-is-erbitux [Accessed 5 Jan. 2019)

Locke J (1689) An Essay concerning Human Understanding Part 2 and Other Writings in *The Works of John Locke*, Vol.2, 1824, 12th Edition, London: Rivington, [online] Available at: https://oll.libertyfund.org/titles/762#Locke_0128-02_643 [Accessed: 14/03/19]

Loftland, J. & Loftland, L., (1995) *Analysing Social Settings*, 3rd Edition, California: Wadsworth Publications Company.

Long Term Conditions Alliance Scotland (LTCAS), (2010) *Emotional Support Matters, Emotional and psychological support needs of people with long term conditions*, [online] Available at: https://www.nes.scot.nhs.uk/media/3223415/alliance_scotland_emotional_support_matters_report_final.pdf [Accessed 15 Sep 2018]

Macedo, F.I.B. & Makarawo, T., (2014) Colorectal hepatic metastasis: Evolving therapies. World Journal of Hepatology, 6(7): pp.453–63.

Mackenzie, N.M. & Ling, L.M., (2009) The Research Journey: A "Lonely Planet" Approach, *Issues in Educational Research*, 19(1): pp.48–60.

Macmillan Cancer Support (2013) *Facing the Fight Alone; Isolation among Cancer Patients*, London: Macmillan Cancer Support.

Macmillan Cancer Support (2015) *Cancer Clinical Nurse Specialists: Impact Briefs*, London: Macmillan Cancer Support.

Macmillan Cancer Support (2018) Cetuximab, [online] Available at: https://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/cetuximab [Accessed 20 Oct 2018]

Macmillan Cancer Support (2018b) CAPOX, [online] Available at: https://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/xelox-or-capox [Accessed 20 Oct 2018]

Macmillan Cancer Support (2018b) Irinotecan with 5FU and folinic acid, [online] Available at: https://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/irinotecan-with-5fu-and-folinic-acid-folfiri [Accessed 20 Oct 2018]

Makhoul, R., Alva, S. & Wilkins, K., (2015) Surveillance and Survivorship after Treatment for Colon Cancer, *Clinics in Colon and Rectal Surgery*, 28(4): pp.262–270.

Malterud, K. (2001) Qualitative research: standards, challenges and guidelines, *The Lancet*, 358(9280): 483-488.

Manfredi S., Lepage C., Hatem C., et al (2006) Epidemiology and management of liver metastases from colorectal cancer, Annals of Surgery, 244(2): pp.254-259.

Martin, R., Paty, P., Fong, Y., et al (2003) Simultaneous liver and colorectal resections are safe for synchronous colorectal liver metastases, *Journal of the American College of Surgeons*, 197(2): pp.233-241.

Martin, R.C.G., Eid, S., Scroggins, C.R. (2007) Health-related quality of life: Return to baseline after major and minor liver resection, *Surgery*, 142(5): pp.676–684.

März, L. & Piso, P., (2015) Treatment of peritoneal metastases from colorectal cancer. Gastroenterology report, 3(4), pp.298–302.

Masera, G., (2010) Hope versus nursing, *Journal of Medicine and the Person*, 8: pp.65-69.

Mason, J. (2002) 'Qualitative Interviewing', in Mason J, *Qualitative Researching*, London: Sage, 62-83.

Maughan, T.S., Adams, R.A., Smith, C.G., et al., (2011) Addition of cetuximab to oxaliplatin-based first-line combination chemotherapy for treatment of advanced colorectal cancer: results of the randomised phase 3 MRC COIN trial, *The Lancet*, 377(9783), pp.2103–2114.

MAXQDA (2020) MAXQDA plus, The art of data analysis, [online] https://www.maxqda.com/products/maxqda-plus [Accessed 5 Feb. 2020]

May, B.J. & Madoff, D.C., (2012) Portal vein embolization: rational, technique and current application, *Seminars in Interventional Radiology*, 29(2): pp.81-89.

Mead, S. & MacNeil, C., (2006) Peer Support: What Makes It Unique? *International Journal of Psychosocial Rehabilitation* 10(2): pp.29-37.

Metcalfe, M.S., Mullin, E.J. & Maddern, G.J., (2004) Choice of surveillance after hepactectomy for colorectal metastases, *Archives of Surgery*, 139(7): pp.749-754.

McCahill, L.E. & Hamel-Bissell, B.P., (2009) The patient lived experience for surgical treatment of colorectal liver metastases: A phenomenological study, *Palliative and Supportive Care,* 7: pp.65-73.

McConnell-Henry, T., Chapman, Y. & Francis, K.F., (2009) Husserl and Heidegger: exploring the disparity, *International Journal of Nursing Practice*, 15:pp.7-15.

McCormack, R., (2014) Gadamer and ALL: A hermeneutic understanding of Academic Language and Learning, *Journal of Academic Language and Learning*, *8*(3), A49-A61, [online] Available at: https://journal.aall.org.au/index.php/jall/article/view/349 [Accessed 15 June 2018]

McDonnell, P. & McNiff, J., (2016) Action Research for Nurses, London: SAGE Publications Ltd.

McHale-Wiegand, D.L., Norton, S. & Baggs, J. (2008) Challenges in conducting end-of-life research in critical care, AACN *Advanced Critical Care*, 19(2): pp.170-177.

McIntyre, R. & Chaplin, J. (2007) Facilitating Hope in Palliative Care, in S.Kinghorn, & S.Gaines, (Eds) *Palliative Nursing: Improving End of Life Care,* Edinburgh: Bailliere Tindall, pp.111-126.

McKie, R. (2015) 'How Britons learned to fight off infection but now die from heart disease and cancer', *The Guardian*, 6 June, [online] Available at: http://www.theguardian.com/society/2015/jun/07/cancer-heart-disease-immunology-british-health [Accessed: 14 Oct. 2015].

McLellan, E., MacQueen, K.M. & Neidig, J.L., (2003) Beyond the Qualitative Interview: Data Preparation and Transcription, *Field Methods*, 15(1): pp.63-84.

McNiff, J. (2013) *Action Research: Principles and Practice*, Oxon: Routledge.

McManus Holroyd, A.E., (2007) Interpretive Hermeneutic Phenomenology: Clarifying Understanding. *Indo-Pacific Journal of Phenomenology*, 7(2): pp.1–12.

Mid Staffordshire NHS Foundation Trust Public Inquiry (2013) *Report of the Mid Staffordshire NHS Foundation Trust*, Public Inquiry, The Stationery Office.

Miller, D.R., (2006) A tribute to Sidney Farber – the father of modern chemotherapy, *British Journal of Haematology*, 134(1): pp20-26.

Miller, D. (2009) *A million miles in a thousand years: what I learned while editing my life,* Nashville: Thomas Nelson.

Miller, H. & King, E. (2015) Good communication is essential to successful integration of health and social care, *The Guardia*n, 17 Feb.,[online] Available at: https://www.theguardian.com/social-care-network/2015/feb/17/good-communication-integration-health-social-care [Accessed: 16 April 2019]

Miller, J., (2007) Hope: A Construct Central to Nursing, *Nursing Forum*, 42(1): pp.12–19.

Moeller, C., (1958) Alert Camus: the question of hope, Cross Currents, 8(2): pp.172–184.

Moene, M., Bergbom, I. & Skott, C., (2006) Patients' existential situation prior to colorectal surgery, *Journal of Advanced Nursing*, 54(2): pp.199-207.

Mohammed, W.M., & Bala, F.K., (2009) Surgical Management of Colorectal Liver Metastases, *Clinics in Colon and Rectal Surgery*, 22(4): pp.225-232.

Monk, R., (2004) Objectivity, postmodernism and biographical understanding: Andrew Collier on R.D. Laing, in *Defending Objectivity: Essays in honour of Andrew Coliier*, M. Archer & W. Outhwaite (Eds), London: Routledge, pp.33-47.

Morecroft, C., Cantrill, J. & Tully, M.P., (2004) Can in-depth research interviews have a 'therapeutic' effect for participants? *International Journal of Pharmacy Practice*, 12(4), pp.247–254.

Morris, E.J.A., Forman, D., Thomas, J.D., et al (2010) Surgical management and outcomes of colorectal cancer liver metastases, *British Journal of Surgery*, 97: pp.1110-1118.

Morse, J.M. & Doberneck, B., (1995) Delineating the Concept of Hope, *The Journal of Nursing Scholarship*, 27(4): pp.277–285.

Morse, J.M., (2015) Critical Analysis of Strategies for Determining Rigor in Qualitative Inquiry, *Qualitative health research*, 25(9): pp.1212–1222.

Moulton, C., Gu, C., Law, C.H., et al (2014) Effect of PET Before Liver Resection on Surgical Management for Colorectal Adenocarcinoma Metastases: A Randomized Clinical Trial, *Journal of American Medical Association* (*JAMA),* 311(18): pp.1863-1869.

Mullens, A.B., McCaul, K.D., Erickson, S.C., et al (2004) Coping after cancer: Risk perceptions, worry and health behaviours among colorectal cancer survivors, *Psycho-Oncology*, 13: 367-376.

Nathan, H. & Wong, S.L., (2016) Treatment of Colorectal Liver Metastases: None of Us Is As Smart As All of Us, *Journal of Oncology Practice*, 12(1), pp.42–43.

National Cancer Action Team, NHS, (2010) Quality in Nursing, Excellence in Cancer Care: The Contribution of the Clinical Nurse Specialist, London, Department of Health.

National Institute for Health and Care Excellence (NICE) (2020) Colorectal Cancer; *The diagnosis and management of colorectal cancer*, Guideline 151, London: NICE.

National Institute of Health Research (NIHR), (2017) *INVOLVE Supporting public involvement in NHS, public health and social care research*, [online] Available at: http://www.invo.org.uk/ [Accessed 25 Oct. 2017].

Naughton, J (2012) Thomas Kuhn: the man who changed the way the world looked at science, *The Guardian*, Sun. 19 Aug. (online) Available at: https://www.theguardian.com/science/2012/aug/19/thomas-kuhn-structure-scientific-revolutions Accessed 15 Oct 2019

NHS UK (2018), *PET Scan*, (online), Available at: https://www.nhs.uk/conditions/pet-scan/ [Accessed 25 Sept 2018)

Nigah, N., Davis, A.J., & Hurrell, S.A., (2012) The Impact of Buddying on Psychological Capital and Work Engagement: An Empirical Study of Socialization in the Professional Services Sector, *Thunderbird International Business Review*, 54(6): pp. 891-905.

Nixon J. (2017) 'Mutual Understanding' in *Hans-Georg Gadamer, The Hermeneutical Imagination*, Hong Kong: Springer, pp.27-40.

Nguyen, M.H., Smets, E.M.A, Bol, N., et al., (2019) Fear and forget: how anxiety impacts information recall in newly diagnosed cancer patients visiting a fast-track clinic, Acta Oncologica, 58(2), pp.182–188.

Nordlinger, B., Guiguet, M., Vailant, J.C., et al (1996) Surgical resection of colorectal carcinoma metastases to the liver: a prognostic scoring system to improve case selection, based on 1568 patients, *Cancer*, 77(7): pp.1254-1262.

Nordlinger, B., Sorbye, H., Gilelius, H., et al (2008) Perioperative chemotherapy with FOLFOX4 and surgery versus surgery alone for resectable liver metastases from colorectal cancer (EORTC Intergroup trial 40983):a randomised controlled trial, *The Lancet* , 371(9617): pp.1007-16.

Nordlinger, B., Poston, G.J. & Goldberg, R.M., (2015) Should the results of the new EPOC trial change practice in the management of patients with resectable metastatic colorectal cancer confined to the liver? *Journal of Clinical Oncology*, 33(3): pp.241–243.

Nurgat, Z.A., Craig, W., Campbell, N.C., et al., (2005) Patient motivations surrounding participation in phase I and phase II clinical trials of cancer chemotherapy, *British Journal of Cancer*, 92: pp.1001-1005.

Nursing Midwifery Council, (NMC), (2018) *The Code: Professional Standards of Practice and Behaviour for Nurses, Midwives and Nursing Associates*, London: NMC.

Nweze, O.J., Agom, A.D., Agom, J.D., et al (2013) A Critical Analysis of the Concept of Hope: The Nursing Perspective, *International Journal of Science and Research*, 4(3): pp.1027-1030.

Oettingen, G. & Wadden, T., (1991) Expectation, fantasy, and weight loss: Is the impact of positive thinking always positive?. *Cognitive Therapy and Research*, 15(2): pp.167-175.

Oettingen, G., (2015) Rethinking Positive Thinking: Inside the New Science of Motivation, New York: Penguin.

Onaca, N., Davis, G.L., Goldstein, R.M. et al (2007) Expanded criteria for liver transplantation in patients with hepatocellular carcinoma: A report from the International Registry of Hepatic Tumors in Liver Transplantation, *Liver Transplantation*, 13(3): pp.391–399.

Orri, M., Revah-Lévy, A. & Farges, O., (2015) Surgeons' Emotional Experience of Their Everyday Practice - A Qualitative Study. *PloS one*, 10(11): pp1-15.

Osborne, J., (1994) Some similarities and differences among phenomenological and other methods of psychological qualitative research, *Canadian Psychology*, 35(2): pp.167-189.

Owen, D.C (1989) Nurses' perspectives on the meaning of hope in patients with cancer, a qualitative study, *Oncology Nursing Forum*, 16(1):pp.75-79.

Oxford University Press (2018) 'Arrive', 'Emotion' 'Expectancy' 'Hope' [online] Available at: https://www.lexico.com/definition/expectancy [Accessed 20 Sep. 2018]

Parahoo, K., (2014) 'Phenomenological Research' in *Nursing Research: principles, process and issues,* 3rd Edition*,* New York: Palgrave Macmillan, pp.211-228.

Passot, G., Chun, Y.S., Kopetz, S.E., et al (2016) Predictors of Safety and Efficacy of 2-Stage Hepatectomy for Bilateral Colorectal Liver Metastases, *Journal of the American College of Surgeons*, 223(1): pp.99–108.

Pawlik, T.M. & Choti, M.A. (2007) Surgical therapy for colorectal metastases to the liver, *Journal of Gastrointestinal Surgery*, 11(8): pp.1057-1077.

Payne, S., Dean, S. & Smith, J., (2006) Low back pain : exploring the meaning of exercise management through interpretative phenomenological analysis (IPA), in L Finlay & C Ballinger

(Eds), *Qualitative research for allied health professionals : challenging choices,* Chichester: Whurr Publishers Limited, pp. 139-155.

Pencovich, N, Houli, R., Lubezky, N., et al (2019) R1 resection of colorectal liver metastasis - What is the cost of marginal resection? *Journal of Surgical Oncology*, 119(3): pp.347–354.

Pergert, P. & Lützén, K., (2012) Balancing truth-telling in the preservation of hope: A relational ethics approach, *Nursing Ethics,* 19(1): pp.21–29.

Petrelli, F., Ardito, R., Ghidini, A., et al (2018) Different Toxicity of Cetuximab and Panitumumab in Metastatic Colorectal Cancer Treatment: A Systematic Review and Meta-Analysis. *Oncology*, 94(4): pp.191–199.

Pietkiewicz, I. and Smith J.A., (2014) A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology, *Psychological Journal*, 20(1,): pp.7-14

Pirie, M., (2019) 'Death and Taxes', *Adam Smith Institute,* [online] Available at: https://www.adamsmith.org/blog/death-and-taxes [Accessed 30 Nov. 2019]

Plato, (2008) *Timaeus and Critias, Translation by R. Waterfield*, Oxford: Oxford University Press, pp.1-100.

Polit, D.F. & Beck, C.T., (2010) Qualitative Designs and Approaches in Polit DF & Beck CT, (eds), *Essentials of Nursing Research, Appraising Evidence for Nursing Practice*, 7th Edition, Philadelphia: Lippincott Williams & Wilkins, pp.258-283.

Polkinghorne, D.E. (1983) *Methodology for the human sciences: Systems of Inquiry,* Albany: State University of New York Press.

Pozzo, C., Barone, C. & Kemeny, N.E., (2008) Advances in neoadjuvant therapy for colorectal cancer with liver metastases, *Cancer Treatment Reviews*, 34:293-301.

Primrose, J., Falk, S., Finch-Jones, M., et al (2014) Systemic chemotherapy with or without cetuximab in patients with resectable colorectal liver metastasis: the New EPOC randomised controlled trial, *The Lancet Oncology,* 15(6): pp.601–611.

Ptacek, J.T. & Eberhardt, T.L., (1996) Breaking bad news: a review of the literature. *The Journal of American Medical Association*, 276: pp.496– 502.

Pui C.H. & Evans, W.E., (2013) A 50-year journey to cure childhood acute lymphoblastic leukemia, *Seminars in Hematol*ogy 50(3): pp.185–196.

Rajakannu, M., Magdeleinat, P., Vibert, E., et al (2015) Sequential liver and lung resection for colorectal cancer metastases: In which patients should surgery be proposed?. *Journal of Clinical Oncology*, 33(15_suppl): pp.3524-3524.

Raleigh, V., Thompson, J., Jabaal, J. et al. (2015) Patients' experience of using hospital services: *An analysis of trends in inpatient surveys in NHS acute trusts in England 2005-13*, London: The Kings Fund.

Randall, F. & Downie, R.S., (2006) 'Critique and reconstruction: some suggestions for a better way', in *The Philosophy of Palliative Care: Critique and Reconstruction*, Oxford: Oxford University Press, pp.199-224.

Raynor (2018) Writing letters directly to patients puts them at the centre of their care, *BMJ Opinion*, Jan. 18, (online) Available at: https://blogs.bmj.com/bmj/2018/01/18/writing-letters-directly-to-patients-puts-patients-at-the-centre-of-their-care/ [Accessed 10 Oct 2019]

Rea, D.J., Heimbach, J.K., Rosen, C.B., et al (2005) Liver Transplantation with Neoadjuvant Chemoradiation is More Effective than Resection for Hilar Cholangiocarcinoma, *Annals of Surgery,* 242(3): pp.451–461.

Reed, E., Simmonds, P. & Corner, J., (2009) Surveying the experience of living with metastatic breast cancer: comparing face-to-face and online recruitment, *Journal of Research in Nursing*, 14(1): 43-55.

Rees, J.R., Blazeby, J.M., Fayers, P., et al (2012) Patient-reported outcomes after hepatic resection of colorectal cancer metastases. *Journal of Clinical Oncology*, 30(12): pp.1364–1370.

Rees, J.R., Blazeby, J.M., Brookes, S.T., et al (2014) Patient-reported outcomes in long-term survivors of metastatic colorectal cancer needing liver resection, *British Journal of Surgery*, 101: pp. 1468-1474.

Regan, R., (2012) Hans-Georg Gadamer's philosophical hermeneutics: Concepts of reading, understanding and interpretation, *Meta: Research in Hermeneutics, Phenomenology and Practical Philosophy,* 6(2): pp.286–303.

Resnik D.B (2015) What is ethics in research and why is it important?, *National Institute of Environmental Health Sciences,* [online] Available at: https://www.niehs.nih.gov/research/resources/bioethics/whatis/index.cfm [Accessed 3 June 2018]

Richards, L., (2015) 'Coding' in L Richards L (Ed) *Handling Qualitative Data: A Practical Guide*, 3rd Edition, London: SAGE, pp.103-124.

Robertson, S.P., (2008) The Qualitative Research Process as a Journey – Mapping Your Course with Qualitative Research Software, *Qualitative Research Journal*, 8(2): pp.81-90.

Rodgers, B.L., (2000) 'Concept analysis: an evolutionary view', in B.L. Rodgers & K.A. Knafi (Eds), *Concept Development in Nursing: Foundations, Techniques and Applications*, 2nd edition, Philadelphia, WB Saunders, pp.77-102.

Rolland, J.S., (2005) Cancer and the family: an integrative model, *Cancer*, 104(11 Suppl): pp.2584–95.

Romans, (2018) Chapter 8, The Bible, *New International Version* (UK), [online] Available at: https://www.biblegateway.com/passage/?search=Romans+8&version=NIVUK [Accessed 5 May 2018]

Rorty, A., (2003) 'Senecca: philosophy as a guide to life', in *The many faces of philosophy: reflections from Plato to Arendt*, Oxford: Oxford University Press, pp.8-13.

Rouslton, K. (2011) Working through Challenges in Doing Interview Research, *International Journal of Qualitative Methods*, 10(4): pp.348-366.

Royal College of Nursing (RCN) (2006) T*elephone advice lines for people with long term conditions, Guidance for Nursing Practitioners*, London: RCN.

Royal College of Nursing (RCN) (2010) Clinical nurse specialists: adding value to care, London: RCN.

Rubin, J. & Rubin, I. (2005) Qualitative Interviewing; The Art of Hearing Data, 2nd Edition, London: Sage.

Ryan, G.W. & Bernard, H.R., (2003) Techniques to Identify Themes, *Field Methods*, 15: pp.85-109.

Saeteren, B., Lindström, U.Å. & Nåden, D., (2011) Latching onto life: living in the area of tension between the possibility of life and the necessity of death, *Journal of Clinical Nursing*, 20(5-6): pp.811–818.

Sanders, J.B, Seda, J.S. & Kardinal, C.G., (2012) The changing hope trajectory in patients with advanced-stage cancer: a nursing perspective, *Clinical Journal of Oncology Nursing*, 16(3): pp.241–242.

Sanoff, H.K., Morris, W., Mitcheltree, A.L., et al (2015) Lack of Support and Information Regarding Long-Term Negative Effects in Survivors of Rectal Cancer, *Clinical Journal of Oncology Nurs*ing, 19(4): pp.444–448.

Sastre, M.T.M., Sorum, P.C. & Mullet, E., (2011) Breaking Bad News: The Patient's Viewpoint, *Health Communication*, 26(7): pp.649–655.

Schensul, J.J., (2012) 'Methodology, Methods and Tools in Qualitative Research' in S.D Lapan et al (Eds) *Qualitative research an introduction to methods and designs*, San Francisco: Jossey-Bass, pp.69-104.

Schiellerup, P., (2008) Stop making sense: the trials and tribulations of qualitative data analysis, Area, 40(2), pp.163–171.

Schleiermacher, F. (1998) Schleiermacher: Hermeneutics and Criticism : And Other Writings, A.Bowie, (Ed), Cambridge: Cambridge University Press, pp.vii-xxxi.

Schlosser, J., (2012) "Hope, Danger's Comforter": Thucydides, Hope, Politics, *The Journal of Politics*, 75(1): pp.169–182.

Schulman-Green, D., McCorkle, R. & Bradley, E.H., (2009) Tailoring Traditional Interviewing Techniques for Qualitative Research with Seriously Ill Patients about the End-of-Life: A Primer, *Journal of Death and Dying*, 60(1): pp.89-102.

Scottish Intercollegiate Guidelines Network (SIGN) (2011) *SIGN 126: Diagnosis and Management of Colorectal Cancer,* Edinburgh: SIGN.

Scottish Medicines Consortium (2018) Cetuximab Advice, (online) Available at: https://www.scottishmedicines.org.uk/medicines-advice/cetuximab-erbitux-fullsubmission-101214/ Accessed 20 Oct. 2018

Selwyn, N., (2014) 'So What?'…a question that every journal article needs to answer, *Learning, Media and Technology,* 39(1): pp. 1-5.

Semino, E., Demjén, Z., Demmen, J., et al., (2017) The online use of Violence and Journey metaphors by patients with cancer, as compared with health professionals: a mixed methods study. BMJ Supportive & Palliative Care, 7(1): pp.60–66.

Shepherd, S.C., Hacking, B., Wallace, L.M. et al., (2019) Randomised controlled trial of a repeated consultation support intervention for patients with colorectal cancer, *Psycho-Oncology*, 28(4): pp.702–709.

Sherwood, L.A., (2015) Managing patients with resectable colorectal liver metastases, C*ancer Nursing Practice*, 14(8): 22-26.

Silverman, D., (2017) *Doing Qualitative Research*, A Practical Handbook, London; Sage, pp.1-96.

Simillis, C. et al., Constantinides, V.A., Tekkis, P.P. et al (2007) Laparoscopic versus open hepatic resections for benign and malignant neoplasms—a meta-analysis, *Surgery*, 141(2): pp.203–211.

Simmonds, P.C., Primrose, J.N., Colquitt, J.L., et al (2006) Surgical resection of hepatic metastases from colorectal cancer: A systematic review of published studies, *British Journal of Cancer*, 94(7): pp.982–98299.

Simpson, M.F. & Whyte, F. (2006) Patients' experiences of completing treatment for colorectal cancer in a Scottish District General Hospital, European Journal of Cancer Care, 15: pp.172-182.

Simpson, G., (2017) *'Buddying' as an intervention to support individuals to access new places or engage in new activities,* CLAHRC NWC, (Collaboration for Leadership in Applied Health Research and Care, North West Coast), Liverpool: CLAHRC.

Sinding, C. & Aronson, J., (2003) Exposing failures, unsettling accommodations: tensions in interview practice, *Qualitative Research*, 3(1): pp.95-117.

Sledge, G.W., (2016) Curing Metastatic Breast Cancer*, Journal of Oncology Practice*, 12(1): pp.6–10.

Stadler, G., Oettingen, G. & Gollwitzer, P. (2009) Physical Activity in Women. *American Journal of Preventive Medicine*, 36(1): pp.29-34.

Stangl, R., Altendorf-Hofmann, A., Charnely, R.M., et al., (1994) Factors influencing the natural history of colorectal liver metastases, *Lancet*, 38(8910): pp. 1405-1410.

Starks, H. & Trinidad, S.B. (2007) Choose Your Method: A Comparison of Phenomenology, Discourse Analysis, and Grounded Theory, *Qualitative Health Research*, 17(10): pp.1372-1380.

Steele, N., Haigh, R., Knowles, G., et al., (2007) Carcinoembryonic antigen (CEA) testing in colorectal cancer follow up: what do patients think? *Postgraduate Medical Journal*, 83(983): pp.612–614.

Smith, J.A., (1996) Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology, *Psychology & Health*, 11(2), pp.261–271.

Smith, J.A., Flowers, P. & Larkin, M., (2009) *Interpretative phenomenological analysis: theory, method and research*, London: SAGE.

Smith, P., (2010) The emotional labour of nursing : the current situation and hereafter, Basingstoke: Palgrave Macmillan.

Smith, P., (2012) The emotional labour of nursing revisited : can nurses still care? 2nd ed., Basingstoke: Palgrave Macmillan.

Snowden, A., Young, J., White, C. et al., (2015) Evaluating holistic needs assessment in outpatient cancer care—a randomised controlled trial: the study protocol. *BMJ Open*, 5(5): pp.1-8.

Snyder, C., (1989) Reality Negotiation: From Excuses to Hope and Beyond, Journal of Social and Clinical Psychology, 8(2): pp.130–157.

Snyder, C. R., Irving, L., & Anderson, J. R. (1991) Hope and health: Measuring the will and the ways, in C. R. Snyder, & D. R. Forsyth (Eds.), Handbook of social and clinical psychology: The health perspective New York: Pergamon Press, pp. 285-305.

Snyder, C.R., (2000) 'Hypothesis: There is Hope' in *Handbook of hope: theory, measures & applications*, C.R. Synder, (Ed), San Diego: Academic Press, pp.3-24.

Snyder, C. (2002) Hope Theory: Rainbows in the Mind. *Psychological Inquiry*, 13(4): pp.249-275.

Snyder, C. (2004) Hope and Depression: A Light in the Darkness. *Journal of Social and Clinical Psychology*, 23(3): pp. 347-351.

Snyder, C., Higgins, R. & Stucky, R., (2005) Excuses: Masquerades in Search of Grace, New York: Percheron Press.

Šolcová, I., (2008) Health as seen by Philosophy of H.G. Gadamer in *Contemporary Discourse on School and Health Investigation,* Brno: MSD*,* pp.101-108.

Sulik G (2010) *Pink Ribbons Blues: How Breast Cancer Culture Undermines Women's Health*, New York: Oxford University Press.

Taylor, C., (1985) 'Self-interpreting animals', in C. Taylor, *Human Agency and Language*, Cambridge: Cambridge University Press, pp.45–76.

Taylor, C., (2001) Patients' experiences of 'feeling on their own' following a diagnosis of colorectal cancer: a phenomenological approach, *International Journal of Nursing Studies*, 38: pp.651-661.

Taylor C., & Gibbs G.R. (2010) 'How and what to code', in Learning Qualitative Data Analysis on the Web, [online] Available at: http://www.acrn.eu/cambridge/downloads/files/How%20and%20what%20to%20code.pdf [Accessed 25 June 2018]

Taylor, I., Garcia-Aguilar, J. & Ward, R., (2010) *Colorectal Disease – Fast Facts*, Oxford: Health Press Limited.

Taylor, R., (2011) 'Epidemiological Realities and Gee Whizz Facts', in *Essential Medical Facts Every Clinician Should Know*, London: Springer, pp. 29-48.

The Cambridge Dictionary, (2018) 'Isolation' [online] Available at: https://dictionary.cambridge.org/dictionary/english/isolation Accessed 12 Nov 2018

The Functional Assessment of Chronic Illness Therapy, (FACIT) (2019) FACT-C, FC-SI, *FACIT*, [online] Available at: https://www.facit.org/facitorg/questionnaires [Accessed 30 Oct. 2019]

The Scottish Government (2008) *Better Health, Better Care,* Edinburgh: The Scottish Government.

The Scottish Government, (2016) *Realising Realistic Medicine, Chief Medical Officer for Scotland annual report 2014-2015*, Edinburgh: The Scottish Government.

The Scottish Government, (2019) *Personalising Realistic Medicine, Chief Medical Officer for Scotland annual report 2017-2018*, Edinburgh: The Scottish Government.

The Scottish Government, (2019) *The Charter of Patient Rights and Responsibilities, NHS Scotland*, Edinburgh: The Scottish Government.

Thompson, N., (2008) Existentialist Ethics: From Nietzsche to Sartre and Beyond, *Ethics and Social Welfare*, 2(1): pp.10–23.

Thorne, S., (2000) Data analysis in qualitative research, *Evidence Based Nursing*, 3: pp.68-70.

Thornton, A.A. & Perez, M.A., (2006) Postraumatic growth in prostate cancer survivors and their partners, *Pyschooncology*, 15: pp. 285–296.

Tilley, D.S., (2011) 'Qualitative Research Methods' in C. Boswell & S. Cannon (eds) *Introduction to Nursing Research, Incorporating Evidence-Based Practice*, 2nd Edition, London: Jones & Bartlett, 193-215.

Todres, L. & Holloway, I., (2010) 'Phenomenological Research', in *The Research Process in Nursing,* 6th Edition, London: Blackwell Publishing Ltd, pp.177-187.

Towsley, G.L., Beck, S.L. & Watkins, J.F., (2007) "Learning to live with it": Coping with the transition to cancer survivorship in older adults. *Journal of Aging Studies*, 21(2), pp.93–106.

Tran, Y., Lamprell, K., Nic Giolla Easpaig, B., Arnolda, G., et al., (2019) What information do patients want across their cancer journeys? A network analysis of cancer patients' information needs, *Cancer medicine*, 8(1): pp.155–164.

Twenzg, C.W. & Aloia, T.A. (2013) Colorectal liver metastases, *Journal Gastrointestinal Surgery,* 17(1): pp.195-201.

Valderrama-Trevino AL., Barrera-Mera B., Ceballos-Villalva J.C., et al (2017) Hepatic Metastasis from Colorectal Cancer, *Euroasian Journal of Hepato-Gasterentology*, 7(2): pp. 166-175.

Van Cutsem, E., Nordlinger, B., & Cervantes, A. (2010) Advanced colorectal cancer: ESMO Clinical Practice Guidelines for treatment, *Annals of Oncology*, 21(5): 93-97.

Van Cutsem, E., Köhne, C.H., Láng, I., et al., (2011) Cetuximab plus irinotecan, fluorouracil, and leucovorin as first-line treatment for metastatic colorectal cancer: updated analysis of overall survival according to tumor KRAS and BRAF mutation status, *Journal of Clinical Oncology*, 29(15): pp.2011–2019.

van Dijk, W., Faber, M.J., Tanke, M.A.C., et al., (2016) Medicalisation and Overdiagnosis: What Society Does to Medicine, *International Journal of Health Policy and Management*, (5): pp.619–622.

van Heinsbergen, M., Den Haan, N., Maaskant-Braat, A.J., et al (2019) Functional bowel complaints and quality of life after surgery for colon cancer: prevalence and predictive factors, Colorectal disease : the official *Journal of the Association of Coloproctology of Great Britain and Ireland*, 22(2), pp:136–145.

van Manen, M., (1997) *Researching Lived Experience. Human Science for an Action Sensitive Pedagogy, 2nd Edition,* London: The Althouse Press.

Van Manen, M., (2014) *Phenomenology of practice : meaning-giving methods in phenomenological research and writing,* California: Left Coast Press.

Venook A.P. & Curley S.A. (2019) Management of potentially resectable colorectal liver metastases, in *UpToDate*, Tanube K.T. (Ed), Waltham, MA, Topic 2483 Version 78.0 [Accessed 25 June 2019]

Verdenius, W.J., (1985) *A commentary on Hesiod Works and days, vv. 1-382*, Leiden: E. J. Brill, pp.66-70.

Vidall, C., Barlow, H, Crowe, M., et al., (2011) Clinical nurse specialists: essential resource for an effective NHS. *British Journal of Nursing*, 20(17): pp.S23–S27.

Vidnes, T.K., Wahl, A.K. & Andersen, M.H., (2013) Patient experiences following liver transplantation due to liver metastases from colorectal cancer, *European Journal of Oncology Nursing*, 17(3): pp.269–274.

Vineis, P. & Wild, C., (2013) Global cancer patterns: causes and prevention, *Lancet*, 383: 9916, pp.549-557.

Wainwright, S.P., (1995) The transformational experiences of liver transplantation, *Journal of Advanced Nursing,* 22: pp.1068-1076.

Wainwright, M. & Russell, A., (2010) Using NVivo Audio-Coding: Practical, Sensorial and Epistemological Considerations, *Social Research Update, University of Surrey*, Issue 60: pp.1-4.

Wagner, J.S., Adson, M.A., Van Heerden, J.A. et al (1984) The natural history of hepatic metastases from colorectal cancer: a comparison with respective treatment, *Annals of Surgery*, 199(49): pp.231-255.

Walker, J., Cassidy, Jim. & Sharpe, M., (2009) The second Symptom Management Research Trial in Oncology (SMaRT Oncology-2): a randomised trial to determine the effectiveness and cost-effectiveness of adding a complex intervention for major depressive disorder to usual care for cancer patients, *Trials*, 10(18): pp.1-8.

Wang, C.C. & Li, J., (2012) An update on chemotherapy of colorectal liver metastases, *World Journal of Gastroenterology*, 18(1): pp.25-33.

Wang, K., Lui W., Yan, X-L., et al (2016) Role of a liver-first approach for synchronous colorectal liver metastases, *World Journal of Gastroenterology*, 22(6): pp.2126–2132.

Warren, M., Mackie, D. & Leary, A., et al (2012) The complexity of non face-to-face work with patients affected by metastatic breast cancer and their carers. The 'hidden consultations' of the clinical nurse specialist (Report), *European Journal of Oncology Nursing*, 16(5), p.460-465.

Watson, R., (2011) *Anatomy and Physiology for Nurses*, 13th Edition, London: Elsevier Health, pp.271-278.

Watt, D., (2007) On Becoming a Qualitative Researcher: The Value of Reflexivity, *The Qualitative Report*, 12(1): pp.82-101.

Weaver, K. & Olsen, J.K., (2006) Understanding paradigms used for nursing research, *Journal of Advanced Nursing*, 53(4): 459-469.

Weeks, J.C., Catalano, P.J., Cronin, A. et al., (2012) Patients' Expectations about Effects of Chemotherapy for Advanced Cancer. *The New England Journal of Medicine*, 367(17): pp.1616–1625.

Weisman, A.D. & Worden, J.W., (1977) The existential plight of cancer: significance of the first 100 days, *International Journal of Psychiatry Medicine*, 7(1): pp.1-15.

Welsh, E. (2002) Dealing with Data: Using NVivo in the Qualitative Data Analysis Process, *Forum: Qualitative Social Research*, 3(2), [On-line] Available at: http://www.qualitative-research.net/fqs/fqs-eng.htm [Accessed 26 June, 2018].

Whale, K. (2016) *"Ahead on points:" Understanding the long-term impact of colorectal cancer with liver metastases on quality of life and survivorship experiences*, PhD, University of the West of England, Bristol.

Wiering, B., Oyen, W.J.G., Adang, E.M.M., et al (2011) Long-term global quality of life in patients treated for colorectal liver metastases, The British Journal of Surgery, 98(4): pp.565–71.

Winner, M., Wilson, A., Ronnekleiv-Kelly S. et al., (2017) A Singular Hope: How the Discussion Around Cancer Surgery Sometimes Fails, *Annals of Surgical Oncology*, 24(1): pp.31–37.

Winter R. & Munn-Giddings C. (2001) *A Handbook for Action Research in Health and Social Care*, London: Routledge, 205-252.

Wong, S.L., Mangu, P.B., Choti, M.A. et al., (2010) American Society of Clinical Oncology 2009 clinical evidence review on radiofrequency ablation of hepatic metastases from colorectal cancer, Journal of Clinical oncology, 28(3), pp.493–508.

Wood, C.B, Gillis, C.R. & Blumgart, L.H. (1976) A retrospective study of the natural history of patients with liver metastases from colorectal cancer, *Clinical Oncology*, 2: pp.285-288.

Worster, B. & Holmes, S., (2008) The preoperative experience of patients undergoing surgery for colorectal cancer: A phenomenological study, *European Journal of Oncology Nursing*, 12(5): pp.418–424.

Worster, B. & Holmes, S., (2009) A phenomenological study of the postoperative experiences of patients undergoing surgery for colorectal cancer, *European Journal of Oncology Nursing*, 13: pp.315-322.

Wright, L. M., Watson, W. L., & Bell, J.M., (1996) *Beliefs: The heart of healing in families and illness*, New York, NY: Basic Books, pp.44-71.

Xie, Si-Ming et al., (2017) Laparoscopic Versus Open Liver Resection for Colorectal Liver Metastases: A Comprehensive Systematic Review and Meta-analysis, *Scientific Reports*, 7(1012): pp.1-10, [online] Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5430829/pdf/41598_2017_Article_978.pdf [Accessed 28 Sept. 2019]

Younas, A. & Porr, C., (2019) Advancing knowledge translation: Is there a role for doctoral students?, *Journal of Advanced Nursing,* 75(5): pp.924-926.

Zeegers, M. & Barron, D., (2015) 'Milestone 6: Method' in M. Zeegers & D. Barron (Eds) *Milestone Moments in Getting Your PhD in Qualitative* Research 1st ed., OXford: Elsevier Science & Technology.

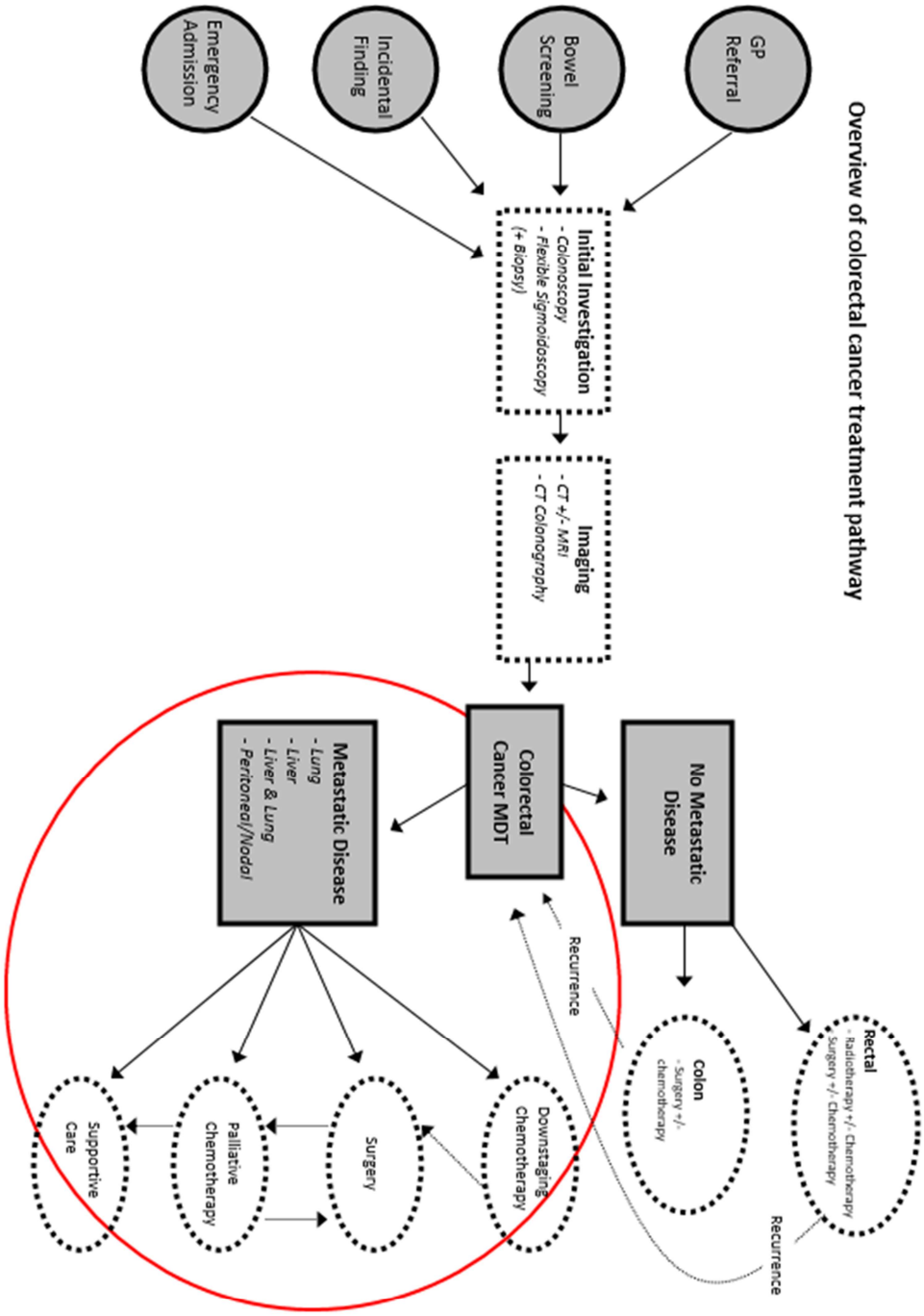
Ziebland, S. & McPherson, A., (2006) Making sense of qualitative data analysis: an introduction with illustrations from DIPEx (personal experiences of health and illness), *Medical Education*, 40: pp.405-414.

Zimmermann, J., (2015) Hermeneutics: A Very Short Introduction, Oxford: Oxford University Press.

Zoellner, T. & Maercker, A., (2006) Posttraumatic growth in clinical psychology: A critical review and introduction of a two component model, *Clinical Psychology Review*, 26(5): pp.626–653.

Appendix I

OVERVIEW OF COLORECTAL CANCER TREATMENT PATHWAY



Appendix II

PARTICIPANT INVITE LETTER

(Patients who proceeded to liver resection)

THE UNIVERSITY of EDINBURGH

NHS Lothian

Date:

Dear

Address:

Invitation to participate in a research project:

Study title: *Supporting patients with colorectal liver metastases: developing an optimal pathway towards surgery*

Thank you very much for taking the time to read this letter. I would like to invite you to take part in a research study. The [area] Bowel Cancer and Liver Teams are very interested to learn more about the experiences of people who have undergone a liver resection for cancer that has started in the bowel. In particular we are keen to hear your views on your time leading up to liver resection. This will include your diagnosis period through to any treatment undergone prior to liver surgery. We understand that this period can be an anxious time for people and we would like to learn from your experiences to help us make improvements to this treatment pathway for future patients.

In order to obtain your input, I would like to invite you to a one-off interview lasting no more than 1 hour. The interview can take place either in your home or at a hospital location, wherever is convenient for you. Your input will be confidential but will be extremely important to us in helping to make change.

Please find an enclosed information sheet giving more detail about the study and what is involved. If you decide that you would like to take part, please contact the study Research Nurse on [number] and leave your name and telephone number. Alternatively, you can return the slip noting your interest in the self-addressed envelope provided. In approximately one week the Research Nurse will contact you by telephone to give you the opportunity to ask any questions you may have about the study. There will be no obligation to take part in the research study. Should you wish to take part, you will be asked to sign a consent form but you can still withdraw at any time.

If you would like to contact an Independent Adviser, who knows about this project but is not directly involved, you are welcome to contact Dr X. Her contact details are given below.

Thank you very much for considering this study.

With best wishes,

Dr Y
Consultant in Medical Oncology

(Addresses of research nurse and independent adviser also included)

Appendix III

PARTICIPANT INVITE LETTER

(patients unable to proceed to liver resection)

THE UNIVERSITY of EDINBURGH

NHS Lothian

Date:

Dear

Address:

Invitation to participate in a research project:

Study title: *Supporting patients with colorectal liver metastases: developing an optimal pathway towards surgery*

Thank you very much for taking the time to read this letter. I would like to invite you to take part in a research study. The [area] Bowel Cancer and Liver Teams are very interested to learn more about the experiences of people who have been considered for a liver resection for cancer that had started in the bowel, but for a number of reasons, have not been able to proceed to an intended liver operation. In particular we are keen to hear your views on your time leading up to when a decision was made not to proceed with liver surgery. This will include your diagnosis period through to any treatment undergone prior to this decision. We understand that this period can be an anxious time for people and we would like to learn from your experiences to help us make improvements for future patients.

In order to obtain your input, I would like to invite you to a one off interview lasting no more than 1 hour. The interview can take place either in your home or at a hospital location, wherever is convenient for you. Your input will be confidential but will be extremely important to us in helping to make change.

Please find an enclosed information sheet giving more detail about the study and what is involved. If you decide that you would like to take part, please contact the study Research Nurse on [number] and leave your name and telephone number. Alternatively, you can return the slip noting your interest in the self addressed envelope provided. In approximately one week the Research Nurse will contact you by telephone to give you the opportunity to ask any questions you may have about the study. There will be no obligation to take part in the research study. Should you wish to take part, you will be asked to sign a consent form but you can still withdraw at any time.

If you would like to contact an Independent Adviser, who knows about this project but is not directly involved, you are welcome to contact Dr X. Her contact details are given below.

Thank you very much for considering this study.

With best wishes,

Dr Y
Consultant in Medical Oncology
(Addresses of research nurse and independent adviser also included)

Appendix IV

PARTIPICANT INFORMATION SHEET

(patient)

THE UNIVERSITY of EDINBURGH

NHS Lothian

Date:

Dear

Study title: *Supporting patients with colorectal liver metastases: developing an optimal pathway towards surgery*

Invitation
Following on from the letter of invitation, this information sheet provides more detail about what would be involved if you decide you would like to take part in this research study. Before making your decision it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information. If you would like something clarified or need more information, please do not hesitate to ask.

What is the purpose of the study?
The purpose of the study is to gain a better understanding of the experiences of patients who have been considered for surgical removal (resection) of part of their liver from a cancer that had started in the bowel. In particular we are keen to hear your views on your time leading up to when a decision was made as to whether it was possible to offer liver surgery. These experiences may be positive or negative. All views expressed will be respected.

Why have I been chosen?
You have been chosen as eligible for the study because you may at some point in your treatment of bowel cancer been considered for liver surgery or have undergone liver surgery. Having gone through this period, your views are especially relevant.

Do I have to take part?
Participation in this study is entirely voluntary. If you decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form. Taking part does not affect your right to leave the study at any time. You do not have to give a reason for leaving the study and it will not affect the standard of any future care.

What will happen if I take part?
You will be contacted by telephone by the researcher who will explain in more detail what participation in the project will involve. This will give you time to ask questions before you decide whether you want to take part.

What will I have to do if I take part?
If you consent to take part in this study you will be asked to participate in a one off interview. This can be conducted in your home or a hospital location, wherever is convenient to you. You do not need to talk about anything if it makes you feel uncomfortable. The aims of the interview in particular are to:-

(1) Identify key time points in the pathway to potential liver surgery, that were critical to your wellbeing and decision making
(2) Identify your expectations and needs in the pathway to possible liver resection
(3) Learn from your views as to how the pathway to potential liver resection could be improved

Appendix IV (cont.)
PARTIPICANT INFORMATION SHEET
(patient)

What are the possible disadvantages of taking part?
There will be a time commitment of approximately one hour. Understandably, some patients may find it difficult to talk about aspects of their cancer treatment. It is important that you know that if there is anything which makes you feel uncomfortable, you do not need to take part. The researcher is available to discuss any anxieties you may have.

What are the possible benefits of taking part?
The findings from this study will help to make improvements to the treatment pathway for patients undergoing liver resection. The pathway often involves demanding treatment and can present stressful challenges to patients and their families which we hope to be able to address through this research. In addition, you may find it helpful to know that others might share your views and these collective views will help us drive forward change.

Will my taking part in the study be kept confidential?
If you agree to take part in the study, it is important that you know that any information you give will be kept strictly confidential. The interview will be conducted by the researcher (name) and will be audio-taped. However, no participants will be publicly identified and all data will be anonymous so it will not be possible for you to be identified. Any data gathered will be kept in a secure place and will be destroyed after the examination process. Access to your medical records may be required during the study and should you agree to participate your GP will be informed.

What will happen to the results of the research study?
The results of the study will be presented in a Masters dissertation for the University of Edinburgh, for NHS [area] and may be published in a journal or presented at a conference. If you would like information about the outcomes of the study, we would be happy to share them with you and copies will be made available by contacting [name] (Principal Researcher) on [number].

Who is reviewing the study?
The study proposal has been reviewed by the [area] Scotland Ethics Service (SRES) and by NHS [area] Research & Development. The study has been given a favourable ethical opinion by SRES.

Who do I contact for further information?
If you would like further information about the study please do not hesitate to contact the researcher, [name], on [number] or leave a message. Alternatively, if you would like to speak to an Independent Adviser you can contact:

Dr Y
Consultant in Medical Oncology
[Address]

What if there is a problem?
If you have a concern about any aspect of this study please contact Dr Y who will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting the NHS [area] Complaints Team based at [address and contact details].

Thank you very much for reading this information sheet.

Appendix V
PATIENT CONSENT

THE UNIVERSITY of EDINBURGH

NHS Lothian

CONSENT FORM

Study title: *Supporting patients with colorectal liver metastases: developing an optimal pathway towards surgery*

Contact details of person taking consent:
Principal Researcher/Research Nurse
Name/Address/Telephone contact number of researcher

Please initial box

1. I confirm that I have read and understand the information sheet (version 3.0, dated x/x/x) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason or without my medical care or legal rights being affected. ☐
3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by the researchers and individuals from the Sponsor or from the NHS organisation, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I understand that interviews will be audio recorded for use by the researcher and then destroyed. ☐
5. I agree to my General Practitioner being informed of my participation in this study. ☐
6. I agree to take part in the above study. ☐

Name of Patient	Date	Signature
Researcher	Date	Signature

Version 3.0
Dated x/x/x

Appendix VI
GP LETTER

THE UNIVERSITY of EDINBURGH

NHS Lothian

Date:

Dear

Study title: *Supporting patients with colorectal liver metastases: developing an optimal pathway towards surgery*

Patient's name:
Address:

The above patient has consented to take part in the named study. This is a qualitative research study being undertaken by [name] (Clinical Nurse Specialist) as part of a MPhil through The University of Edinburgh. The study has the interest and support of the [name] Multidisciplinary Colorectal Cancer Team.

The aim of this study is to explore the experiences of patients who have been offered a hepatic resection for cancer originating from a bowel primary. Patients will be asked to participate in a one-off interview lasting approximately 60 minutes in a setting convenient to them. We are particularly interested in hearing the experiences of patients at time of diagnosis, treatment undergone prior to liver surgery and on the time when a decision regarding liver resection was made. The study will include interviews with patients who have proceeded to successful liver surgery and those who have not. Understandably this period can be difficult for patients and the experiences of patients will be used to improve the care pathway for future patients who are being considered for resection of colorectal liver metastases.

The study has been granted ethical approval by the Integrated Research Approval Committee and The University of Edinburgh.

The independent adviser for this study is Dr Y, Consultant in Medical Oncology, [address and contact details].

Should you require any additional information, please do not hesitate to contact myself or Dr X directly.

Yours sincerely,

Dr Y
Consultant in Medical Oncology

(Addresses of research nurse and independent adviser also included)

Appendix VII
HEALTH CARE PROFESSIONAL INVITE LETTER
(pre revised pathway)

Date:

Dear

Invitation to participate in a research focus group

Study title: *Supporting patients with colorectal liver metastases: developing an optimal pathway towards surgery*

As you know I was successful in securing a grant to conduct a research study looking at the experiences of patients being considered for surgical resection of liver metastases originating from a bowel primary. I am also undertaking postgraduate study at The University of Edinburgh to help to inform and guide the study. Observationally, it is recognised that the workup and decision making involved prior to a possible liver resection is incredibly demanding for patients. Initially I am going to conduct interviews with patients who have undergone surgical resection of liver metastases and with patients for whom it has not been possible to proceed to liver resection. In addition to gaining the experiences of patients, I am keen to obtain the views of health care professionals involved in the pathway.

In order to obtain your input, I would like to invite you to attend a small focus group (lasting 60 minutes) with 6-8 health professionals involved in the liver resection pathway. The focus group will be audio-recorded but you will not be identifiable through any data collection.

The findings from the patient and health care professionals focus groups will be analysed to identify common themes. These findings will then be used to plan a service change along with the study steering group. The second stage of the study will involve an evaluation of the changes made by further patient interviews.

Should you need further information, I would be more than happy to help. Alternatively, Dr X is also acting as an Independent Adviser and can be contacted on the number below.

Yours sincerely,

[name]
Clinical Nurse Specialist, Colorectal Cancer

(Addresses of research nurse and independent adviser also included)

Appendix VIII
HEALTH CARE PROFESSIONAL
INFORMATION SHEET

THE UNIVERSITY of EDINBURGH

NHS Lothian

Dear

Study title: *Supporting patients with colorectal liver metastases: developing an optimal pathway towards surgery*

Invitation
Following on from the letter of invitation, this information sheet provides more detail about what would be involved if you decide you would like to take part in this research study. Before making your decision it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information. If you would like something clarified or need more information, please do not hesitate to ask.

What is the purpose of the study?
The proposed study is a piece of action research, seeking to elicit the experiences of patients and health care professionals involved in the pathway to surgical resection for colorectal liver metastases and then use these findings to drive forward a service change. As a team we know that the pathway to liver resection is incredibly demanding for patients. Anecdotal evidence from patients suggests that balancing issues of hope with realistic treatment options can be especially difficult throughout the pathway to liver resection. With little available in the literature to support this, a patient experience study is necessary to identify the needs of patients during this time.

The study will be conducted in two phases. Phase 1 will include patient interviews with those who have been considered for surgical resection of liver metastases, including patients who were able to proceed to surgical resection and those who were not. Phase 1 will also include a focus group with health care professionals involved in the liver resection pathway to gain their experiences and perceptions of the current pathway. An interim period will evaluate the findings from the patient interviews and health care professional focus group. The researcher, with the support of a steering study group will assess potential changes in the pathway and consider what additional nursing interventions can be offered to support patients through this demanding pathway. The model of nursing intervention will be dependent on the findings from Phase 1.

Phase 2 will involve interviewing a further patient sample group who have been considered for liver resection following implementation of the service change. A further focus group with health care professionals will also be conducted to ascertain change or initiate further change.

Why have I been chosen?
You have been chosen as eligible for the study because you are routinely involved in the direct care and pathway of patients being considered for surgical resection of liver metastases and as such your views are crucial to initiating change.

Do I have to take part?
Participation in this study is entirely voluntary. If you decide to take part, you will be asked to sign a consent form prior to the focus group. You may of course, leave the study at any time.

Appendix VIII (cont.)
HEALTH CARE PROFESSIONAL INFORMATION SHEET

What will happen if I take part?
If you agree to participate, you will be contacted by the researcher who will co-ordinate a suitable date, time and venue to conduct the focus group.

What will I have to do if I take part?
If you consent to take part in this study you will be asked to participate in a one off focus group. This will be conducted at the [location name].The researcher will conduct the focus group, using open questions based on similar questions posed to patients during the patient interviews. The aims of the focus group in particular are to:-

(1) Identify key time points in the pathway critical to the well wellbeing and decision making of patients
(2) Identify how health professionals manage patient hope and expectation during the pathway to possible liver resection
(3) Listen to your views as to how the current pathway could be improved

What are the possible disadvantages of taking part?
There will be a time commitment of approximately one hour, which understandably will need to be considered with your regular work commitments.

What are the possible benefits of taking part?
The findings from this study will help to make improvements to the treatment pathway for patients undergoing liver resection. The pathway often involves demanding treatment and can present stressful challenges to patients and their families which we hope to be able to address through this research.

Will my taking part in the study be kept confidential?
If you agree to take part in the study, it is important that you know that any information you give will be kept strictly confidential. The interview will be conducted by an independent facilitator and will be audio-taped. However, no participants will be publicly identified and all data will be anonymous.

What will happen to the results of the research study?
The results of the study will be presented in a Masters dissertation for the University of Edinburgh, in a final report to NHS [area] and may be published in a journal or presented at a conference.

Who is reviewing the study?
The study proposal has been reviewed by Scotland Ethics Service (SRES) and NHS [area] Research & Development. The study and has been given a favourable ethical opinion by SRES.

Who do I contact for further information?
If you would like further information about the study please do not hesitate to contact the researcher, [name and contact details] or leave a message. Alternatively, if you would like to speak to an Independent Adviser you can contact:

Dr X
Consultant in Medical Oncology
[Address]

What if there is a problem?
If you have a concern about any aspect of this study please contact Dr X who will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting the NHS [area] Complaints Team based at [address and contact details]

Thank you very much for reading this information sheet.

Appendix IX
EXAMPLE INTERVIEW QUESTIONS AS AIDE MEMOIRE

THE UNIVERSITY of EDINBURGH

NHS Lothian

Study title: *Supporting patients with colorectal liver metastases: developing an optimal pathway towards surgery*

Setting the scene

- Thank-you for taking part.
- Introduction re myself, study and opportunity to ask questions. Length of expected interview.
- Use and purpose of interview recording. No obligation to respond to any questions that make participant feel uncomfortable.
- Consent taking.

Schedule

Introductory questions

(1) Can you provide some background and outline how your bowel cancer was initially diagnosed? At which point was the liver noted to be involved as having spread from your bowel?
(2) Can you outline what treatment you underwent up to the time of liver surgery?
(3) What was your experience of this treatment? How did it affect your quality of life?

Focusing questions - Pathway to liver surgery

(4) What words come into mind when you remember being told that the cancer had spread into the liver?
(5) How did this change when you had a consultation that first talked about the possibility of a liver operation?
(6) What were your expectations prior to this consultation and after the consultation? How was hope conveyed? In what way?
(7) What was your experience of the length of time you waited before liver surgery took place?
(8) What was your experience of the communication from members of the healthcare team during this time?

Focusing questions - Information and support

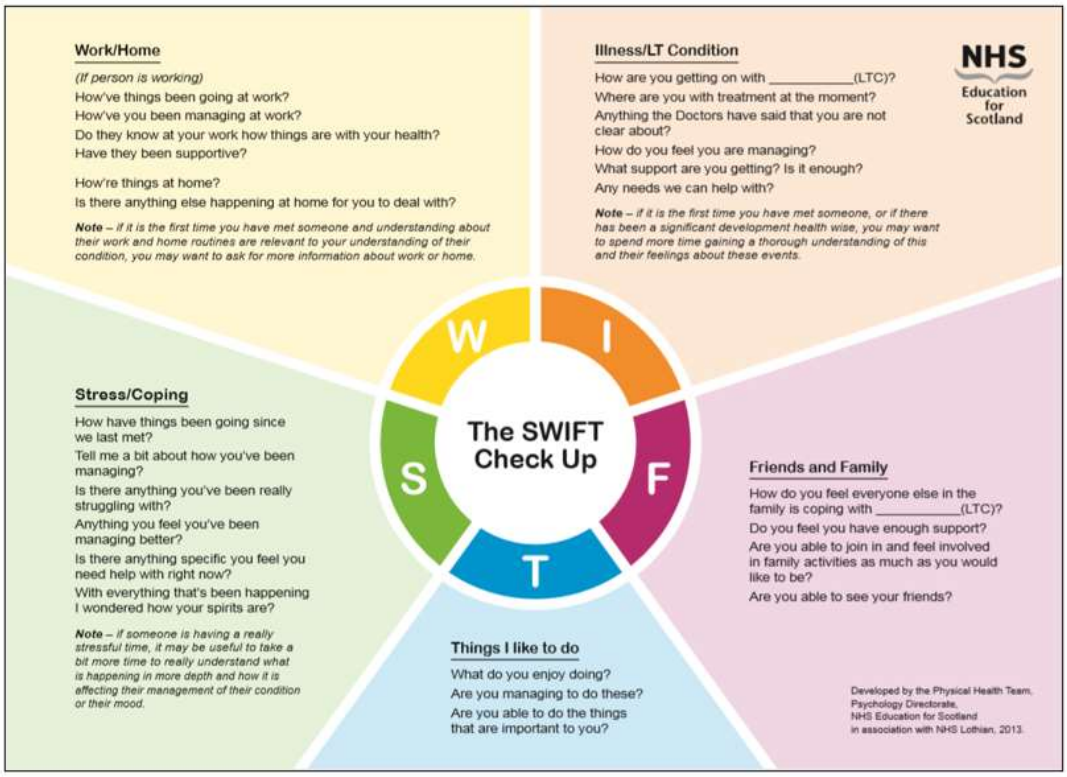
(9) Did you at any point seek further information? Did you access the internet and if so, how helpful did you find this?
(10) From where/who did you seek support during this time?
(11) Did you ever experience low mood or anxiety during this time? Were any measures taken to address this?
(12) What impact did this period have on your friendships, family life or working life?

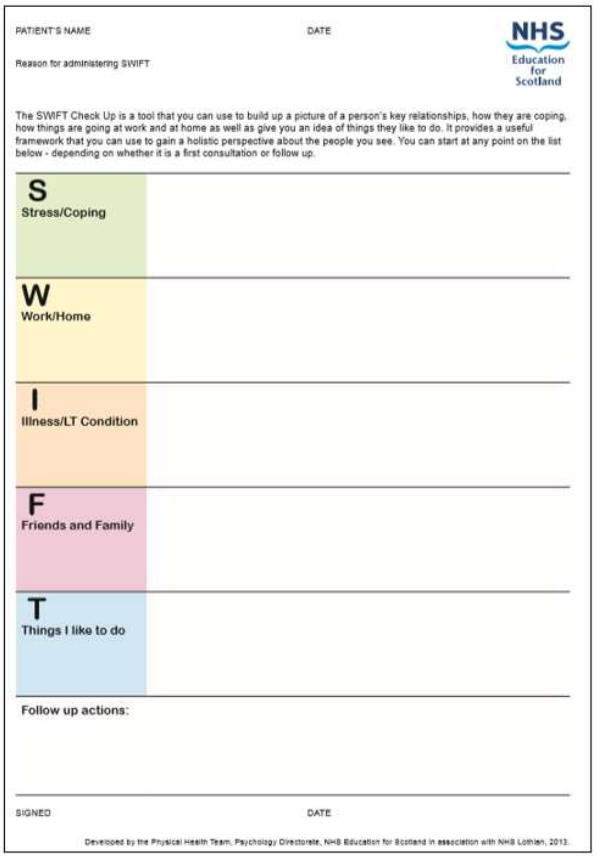
Closing questions

(13) Looking back, can you identify critical timepoints that were important in your path to liver surgery?
(14) Overall, is there anything that worked well or could have been improved on?
(15) Anything further to add?

Thank-you

Appendix X
SWIFT tool and template





Appendix XI

Liver series, leaflet 1 -When bowel cancer spreads to the liver: Understanding surgical management

(for A4 printing in tri folded position)

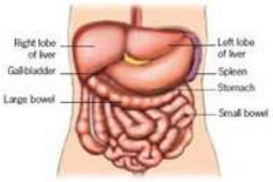
Introduction
This booklet is designed to help you and your family understand more about the pathway to surgical removal of a liver secondary from a bowel cancer. If you need more information or have further questions, please ask a member of your care team.

What is a liver secondary?
Our bodies are made up of tiny structures called cells that cannot be seen by the naked eye. Normally these cells reproduce themselves by dividing in a regular fashion. When cell growth becomes uncontrolled, a cancer occurs.

When a cancer forms in a part of the body, a few cancer cells may break off and find their way into the bloodstream. Because your liver filters your blood, any cancer cells in the bloodstream can settle in the liver to form a secondary cancer, often called a metastasis. This is not the same as a 'liver cancer and we still call this 'bowel cancer' as this is where the cells originally came from.

Diagnosing a liver secondary
Some people will be diagnosed with a bowel cancer and a liver secondary at the same time. For others a liver secondary will be diagnosed during a period of follow-up after treatment for bowel cancer. All patients found to have liver secondaries will have blood tests and specialist scans to work out how far the cancer has spread. These may include CT, MRI and PET scans, which help identify the exact location(s) of the disease.

Role and location of the liver
The liver is the major factory for your body. It lies on the right hand side of the body under your ribs and is divided into two main parts called the right lobe and the left lobe (*see diagram).* It is a common site for bowel cancer secondaries.



The liver has many important functions including:
- producing proteins which help blood to clot and prevent excessive bleeding
- destroying harmful substances to get rid of waste products
- breaking down foods containing sugars and fats so the body can use them for energy
- producing bile, which is used by the body to break down fats in food so they can be absorbed in the bowel.

Up to 75-80% of your liver can be safely removed at surgery as the liver is very good at re-growing itself. After surgery, the liver takes approximately 8-10 weeks to re-grow.

Multi-disciplinary management
Planning the right treatment for you is essential, therefore the management of a liver secondary uses a team approach. Your results will be discussed with a specialist multi-disciplinary team of doctors, surgeons, nurses and other health professionals.

It is likely that your care will start with the colorectal team based at the Western General Hospital. If your cancer has spread to your liver you will be referred to other specialist teams. The oncology team is based at the Western General and the liver team at the Royal Infirmary of Edinburgh.

Getting the right treatment decision is important and expert opinion and review of scans can take several weeks before a final plan of treatment is made. Your treatment plan will reflect whether you have had surgery or chemotherapy for bowel cancer before and may include surgery on your bowel, a period of chemotherapy and/or surgery on the liver.

Occasionally if the liver secondary is diagnosed at the same time as a bowel cancer, it may be possible to carry out a combined operation on the liver and bowel. If not, it may be possible to operate on the bowel and liver separately. While your treatment is being planned, you may meet the following members of this team:

- **Colorectal/ liver surgeon.** This is a surgeon who will carry out your operation or surgical procedure, should one be necessary. Your surgeon will be a specialist in your particular type of cancer.
- **Oncologist.** This is a doctor who specialises in treating cancer patients. They have expert knowledge in chemotherapy and radiotherapy treatment. If necessary you will see an oncologist to discuss the advantages of chemotherapy and/or any other treatments or trials.
- **Nurse specialist.** These nurses provide information and support for you and your family throughout your care.

They can help with any physical, emotional or social concerns you may have. They deal specifically with patients with cancer and work as part of your specialist team to co-ordinate your care.

Once a plan has been made, a clinic appointment will be made for you to see a specialist as an outpatient. Your consultant will take everything about your illness into account and will recommend an individually tailored programme of treatment for you. At each step they will explain what care and treatment options are available to you. Your specialist/support nurse will try and explain anything you are uncertain or concerned about.

Planning the right treatment for you
Chemotherapy: Chemotherapy uses anti-cancer drugs to destroy cancer cells and is a common treatment for secondary cancer in the liver. It can destroy cancer cells circulating in the blood and those that have settled in the liver. It may be used
- before and/or after liver surgery to reduce the likelihood of the cancer returning
- to try to shrink secondary liver cancer to allow removal by an operation
- as the only treatment for liver secondaries where surgery is not possible.

The standard chemotherapy drugs for colorectal liver secondaries are the same ones used to treat bowel cancer. You may need several courses of chemotherapy. Your oncologist will discuss everything with you in clinic.

Surgery: Surgery usually aims to remove all the cancer from your liver in one operation. Sometimes there is not enough 'normal' liver to allow this and surgery is done in several stages.

Your liver surgeon will assess your fitness for surgery and discuss the details of the surgery planned individually for you in clinic.

Other liver treatments: If liver surgery is not recommended, treatments including radiofrequency ablation (RFA) or selective internal radiotherapy treatment (SIRT) may be offered, often as part of a clinical trial.

Follow up
This will be tailored according to your individual situation. If you have had liver surgery you will often be seen once for follow up by the liver surgeon and then be followed up by your original cancer team. You will have at least six monthly clinic visits, blood tests and CT scans for 3 years.

Further information and support
We recognise that this time can be stressful and it is important you get adequate support. Your nurse specialist will help during this time and can also put you in touch with local support and information services. If you wish, they can put you in touch with someone else who has had liver surgery and undergone a similar experience to yourself.

You may also find the following websites useful:
www.macmillan.org.uk
www.cancerresearchuk.org
www.beatingbowelcancer.org
www.maggiescentre.org

Colorectal Cancer Nursing Team,
Western General Hospital
Monday-Thursday 9am - 4pm
0131 537 2239.

NHS Lothian

When bowel cancer spreads to the liver:

Understanding surgical management

Information for patients, relatives and carers

Colorectal and Hepatobiliary Teams,
NHS Lothian

Review date: October 2016

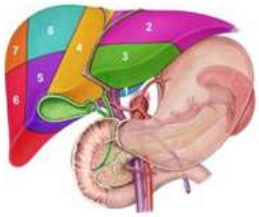
Appendix XII

Liver series, leaflet 2 - When bowel cancer spreads to the liver: Your surgery

(for A4 printing in tri folded position)

Introduction
This booklet has been designed to help you and your family understand what is involved in a liver operation when bowel cancer has spread to the liver. If you need more information or have further questions, please ask a member of your care team.

What is a liver resection?
A liver resection (hepatectomy) is an operation to remove part of your liver. This can also include removing the gallbladder. Liver resection is a major operation that can take 3-6 hours. It is performed because it is the most effective way to remove the tumour/s (metastases) in your liver. The liver is made up of two lobes which, for reference, are divided into eight segments (see below).



Your surgery will be guided by the location of the tumour. A small number of people have a liver resection at the same time as bowel surgery. This is known as a 'synchronous resection' and you will be advised if this is possible or required.
The liver is very good at re-growing itself, so up to 75-80% of your liver can be safely removed. After surgery, the liver takes approximately 8-10 weeks to re-grow.

Before your operation
To prepare you for your surgery, you will meet with your surgeon in the outpatient department. He/she is a specialist in liver surgery and is known as a hepatobiliary or HPB surgeon. At this appointment we will assess your overall health and discuss the risks and benefits of surgery. In some cases another procedure may be arranged before surgery to make sure there is enough 'good' liver to cope after liver surgery. This will be discussed, if required.

Questions are welcome. Before coming to your clinic visit, you may want to write some questions down and bring them to clinic with you.

Pre-assessment clinic
Before your liver surgery, we will give you an appointment to attend a pre-assessment clinic. Allow approximately half a day for this appointment. It is useful if you can bring a list of any current medication with you. A detailed medical history and physical examination will be carried out. We will also take some blood samples. Any additional investigations such as ECG (echocardiogram) or X-ray will be performed at this time, if needed.

At this appointment we will give you a green leaflet called *'You and your anaesthetist'*. This contains useful information about preparing for surgery and pain management during surgery and after surgery.

Your operation
Your operation may be an open operation or a laparoscopic (keyhole) operation. This will be discussed at the time of your clinic appointment. Your operation will in general be carried out by the consultant you met at clinic and their specialist team.

Before your surgery you will be asked to sign a consent form so that you understand:

- the type of treatment recommended for you
- advantages and disadvantages of the treatment
- any significant risks or side-effects of treatment.

The Royal Infirmary of Edinburgh is a major centre for liver transplantation. It is possible that we may have to cancel your liver surgery on the day of your operation and rearrange your surgery for another day because we need to perform a liver transplant.

We understand that preparing for major surgery and then being sent home is very disappointing. Due to the preciousness of donor livers, we have no control over this and it may help if you know this is a possibility.

During your operation
During your operation you will be looked after by a team of surgeons, anaesthetists and theatre nurses. They will monitor you closely until you are fully awake. Your surgeon will send samples of the liver that they remove to the laboratory for examination. The results will be available for you at the time of your follow-up clinic.

What happens after the operation?
After your operation you will be cared for in the High Dependency Unit (HDU) for a few days. HDU is a specialised area where we can closely monitor your breathing, blood pressure and kidney function. When the surgeon and the anaesthetist decide you are fit enough, you will return to the ward to continue your recovery.

Pain management
You will need painkillers after your surgery. The ways of giving pain relief will be discussed before your operation, e.g. an epidural or patient controlled analgesia (PCA). Your pain relief will be assessed regularly and gradually changed to oral painkillers before you leave hospital.

Tubes and drains
After your operation you will need extra oxygen to breathe for a few days. You will be given fluid through a drip until you can eat and drink normally. An abdominal (tummy) drain may be placed at the time of your operation and will be removed as you recover. You will also have a urinary catheter. This tube leads from your bladder and drains your urine into a bag until you are able to be up and about.

Physiotherapist
The physiotherapist will show you how to practice deep breathing exercises and move around. After major surgery it is very important to move around to reduce your risk of a chest infection or a deep venous thrombus (DVT), also known as a blood clot. You may have to wear surgical stockings in hospital to reduce this risk and have a daily injection of a blood-thinning medicine.

Abdominal wounds
Abdominal wounds usually heal without any problems but sometimes they become infected and open up slightly. Usually this won't stop you going home, but the wound needs to be covered by a dressing until it heals. Dressings can be changed by the practice nurse/district nurse when you are at home and your clips should be removed around 10 days after the operation.

How long will I be in hospital?
We use enhanced recovery after surgery (ERAS), which encourages you to take an active part in your recovery. You will normally be in hospital for 3-5 days after a liver resection, or possibly longer if there have been complications. Going home can be an emotional time. You may be looking forward to going home but have concerns about how you will manage. These feelings are normal.

Recovery
It can take up to three months to be fully fit after a liver resection. It is normal to feel very tired after discharge. Most people benefit from a set period of rest during the day. You should aim to gradually increase your activity. Please see the separate leaflet *'Recovery after Liver Surgery'*.

Follow-up
This will be tailored according to your individual situation. If you have had liver surgery you will often be contacted or seen within 4-6 weeks. You will then be followed up by your original cancer team. You will have at least six monthly clinic visits, blood tests and CT scans for three years.

Sources of further information and support
You may find it helpful to speak to someone else who has been through a similar experience. Your nurse specialist can put you in touch with someone who has had liver surgery. In addition, you may find the following support agencies useful:

www.macmillan.org.uk www.cancerhelp.org.uk
www.cancerresearchuk.org
www.beatingbowelcancer.org
www.maggiescentre.org

Hepatobiliary Nurse Specialist
Royal Infirmary of Edinburgh
0131 242 3652

Colorectal Cancer Nursing Team
Western General Hospital
0131 537 2239

NHS Lothian

When bowel cancer spreads to the liver:

Your surgery

Information for patients, relatives and carers

Colorectal and Hepatobiliary Teams, NHS Lothian

Review date: October 2016

Appendix XIII

Liver series, leaflet 3 - When bowel cancer spreads to the liver: Your recovery from surgery

(for A4 printing in tri folded posiiton)

Introduction
The purpose of this booklet is to help you and your family understand more about your recovery following your recent liver surgery and return home. It covers questions often asked by patients but if you need more information or have further questions, ask a member of your care team. Please remember that this leaflet is a guideline only and recovery rates are very individual.

The recovery process after liver surgery
A liver resection (hepatectomy) is a major operation. In your case it has been performed because it is the most effective way to remove the tumour/s (metastases) in your liver. Your recovery will depend on the following factors:

- Extent of surgery
- Type of surgery
- Past medical history
- Any post-op complications.

Rest and activity
Re-growth of the liver takes approximately 8-10 weeks and during this time we would encourage you to take a balanced approach to activity and rest. After leaving hospital it is quite normal to feel tired and you may need more sleep than usual. You may benefit from having a set 'rest time' during the day. Try to limit day time sleep to 30 minutes at a time so you can sleep at night. You may need a morning and afternoon rest time.

During your early recovery you may feel emotionally upset. This is normal. Try to be patient with yourself and allow yourself time to get over the operation. Recovery times vary. Some people can take up to 3-6 months before their fitness and energy levels return to pre-op levels. It is key to adopt a positive attitude to recovery, setting realistic weekly goals. Many patients say this is a beneficial approach that gives them a sense of control. If you would like help with setting achievable goals, please speak to a nurse specialist.

Wound healing
The size of your wound will depend on the type of surgery you have had. If you had an open procedure you will have a larger wound. If you had laparoscopic surgery you will have 2-3 small cuts. Avoid using strong creams or soap around wound areas. Once the dressing has been removed and it appears clean and dry, the wound can be left without a dressing.

Abdominal wounds usually heal without any problems but occasionally they become infected and open up slightly. Usually this will not stop you going home and can be managed by a community nurse at home. Clips will be removed 10 days after your operation by your district nurse/practice nurse. Dissolvable stitches will not need to be removed.

Wound healing takes place over a period of time. If the wound becomes red, inflamed, painful, or starts discharging, please contact your GP or NHS 24 as it may indicate infection. It is normal for the wound to itch or tingle and feel slightly numb. It may also feel hard and lumpy. We advise you not to pull off any scabs. As the wound heals you may feel tightness and pulling around the wound. Again, this is normal.

Pain control
You will leave hospital with a supply of painkillers. If these are not effective or you need a further supply, please contact your GP. Pain control helps with your ongoing recovery.

Bathing and showering
While you are on the ward you can shower and bath as normal. At home, it may be sensible to have someone in the house when you have your first bath or shower.

Appetite/ Alcohol
At first, expect to have a reduced appetite. You may find it helpful to take a 'small and often' approach to eating. A diet high in protein and calories is essential to aid recovery. Some patients may need supplement drinks at first. The aim is to get back to eating a balanced healthy diet. We advise you to avoid alcohol in the period after your operation while your liver recovers from the surgery. When resuming alcohol you should keep within the national government guidelines.

Bowel activity
A temporary change in bowel function is normal after surgery. The effect of anaesthetic and painkillers means it is not uncommon to have constipation or very occasionally diarrhoea. Please seek advice if this becomes a problem.

Sleep
It is normal for sleep patterns to be disturbed after an operation. Finding your own sleep pattern at home may take several weeks but this will improve over time. Some people may need medication for a short time to help regain their sleep pattern.

Driving
Before driving, you should ensure that you can do a full emergency stop and be able to respond quickly to any situation. If you are not fit to drive you may invalidate your insurance. You should contact your insurance company about the terms of your policy as they can vary.

Returning to normal activities
A phased return to activity is advised. Walking a short distance every day is beneficial, increasing distances gradually over a period of weeks. Resume light household duties (e.g. dusting / dishes) in the first 1-2 weeks before working up to heavier tasks. Avoid heavy lifting and vigorous exercise for 4-6 weeks (e.g. heavy gardening). You can resume sexual activity when you and your partner feel comfortable. On average, most people return to work after four weeks. However if you have a heavy manual job, you may need longer off work. Returning to work is dependant upon your recovery and further consultation with your GP. It is often good to discuss flexible return to work with your employer.

Frequently asked questions

Holiday insurance
Insurance is advised if travelling abroad. Maggie's Centre or Macmillan Centres provide up-to-date advice on competitive insurers.

Coping financially
Advice on benefits can be accessed through Macmillan Centres, or Maggie's. If you are in doubt, please contact your nurse specialist.

Results and further treatment
Any results from your surgery will be discussed with you in person at the first appointment after you leave hospital. Any indication for further treatment will be discussed at this appointment.

Follow-up
This will be tailored according to your individual situation. If you had liver surgery you will often be contacted or seen within 4-6 weeks. You will then be followed up by your original cancer team and will have at least six-monthly clinic visits, blood tests and CT scans for three years.

When should I seek help?
If you have any concerns after you leave hospital, your first point of contact will be your GP practice during working hours. You should contact NHS 24 on **111** outwith this time. You can also seek advice from your nurse specialist.

Sources of further information and support
We recognise that you may find it helpful to speak to someone else who has been through a similar experience. Your nurse specialist would be able to put you in touch with someone who has undergone liver surgery. In addition you may find the following support agencies useful:

www.macmillan.org.uk; www.cancerhelp.org.uk
www.cancerresearchuk.org
www.beatingbowelcancer.org
www.maggiescentre.org

Hepatobiliary Nurse Specialist, Royal Infirmary of Edinburgh. 0131 242 3652.
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